



**Proxy respondents in a case-control study:  
validity, reliability and impact**

*by*

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## **Abstract**

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In many research settings, the study subject is unable to provide responses, requiring researchers to find alternative respondents. This thesis explores the use of proxy respondents in a case control study of premature mortality among Russian men of working age (25-54 years).

Data obtained from proxy respondents is explored in four ways. Firstly, proxy questionnaire responses are validated against external data sources which were routinely collected, blind to case-control status – the city alcohol treatment clinic (Narcology Dispensary), Social Security and Police records. Secondly, agreement between proxy and index (control) responses to questions about alcohol use, tobacco use, health and socioeconomic factors is explored. Thirdly, the effect of proxy type is explored by examination of proxy-proxy and index-proxy agreement in a subset of households in which two proxy interviews were obtained. Finally, the impact on analysis outcomes is explored by mortality analyses using proxy versus index data.

Cohen's kappa coefficient was used to explore inter-respondent agreement. Differences in agreement between pairs of respondents were examined using Agresti's loglinear model, and the directionality of disagreements were evaluated using McNemar's test.

Findings confirm some assertions in the literature. Questions about easily observable characteristics and behaviours, avoiding excessive detail, subjective or sensitive topics, elicit valid proxy responses. Proxies tend to over-report alcohol use, but provide particularly valid responses about tobacco use and socioeconomic factors. Validity was highest among proxies who were the index's spouse. However, further exploration suggested that men who have spouses differ in their behaviour from men who do not in ways which affect its reporting. There was little additional evidence that proxy characteristics affect validity. The use of proxy responses biases odds ratios in this case control study toward more conservative estimates. These findings are generalisable to study settings which employ a protocol to ensure selection of the best available proxy.

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## **Personal contribution to this thesis**

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I was employed as a research fellow for the Izhevsk Family Study from September 2002 until its completion, and played a key role in the development of certain aspects of its design. I carried out an initial literature review in to the quality of proxy respondents which fed directly into questionnaire development: an updated version of this review is found in Chapter 1. I also carried out a series of kappa analyses on the control-proxy agreement observed in data collected during the last piloting phase, the findings of which again fed directly into the questionnaire development and are found in Appendix 4. I was responsible for the detailed drafting of the questions in the three questionnaires (for the case proxy, control proxy and control) which are described in section 3.6.1. I was also responsible for the development and overseeing of the piloting phases in Izhevsk, and for development of the protocol for selection of proxy respondents and validation interviews. In addition, I was the overall coordinator of the project throughout the development phase, and played a key role in data cleaning and analysis both during and after the fieldwork phase, taking responsibility for the creation and documentation of a full analytic dataset which was made available to the study team via a secure website which I designed, created and maintained. I have visited Izhevsk more than 10 times.

The work presented in this thesis is my own.



## **Aims**

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This thesis aims to assess the validity and reliability of proxy respondents in a case-control study of premature mortality, particularly with respect to alcohol.

Specifically:

1. To systematically review the existing literature on validity of proxy respondent data in observational studies
2. To investigate the validity of data provided by proxy respondents using data collected by a major case-control study of premature male mortality in Russia.  
Specifically, to:
  - (i) investigate the validity of proxy respondents with respect to external data.
  - (ii) investigate the validity of proxy respondents with respect to index respondents.
  - (iii) investigate the importance of the index-proxy relationship.
3. To investigate the impact of proxy respondent data on estimates of the strength of associations between alcohol and other factors and mortality

# **Chapter 1 Does it matter who we ask? The validity of proxy respondents in observational studies – a literature review**

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## **1.1 Summary of chapter contents**

In epidemiology we sometimes need to obtain exposure information about individuals unable to provide it themselves. One approach to addressing this problem is the use of secondary, or proxy, respondents as informants about the subject (the index). Use of this methodology raises the question of whether data obtained from proxy respondents is valid. This chapter examines the extant literature investigating the validity of proxy responses with respect to index responses.

## **1.2 Background**

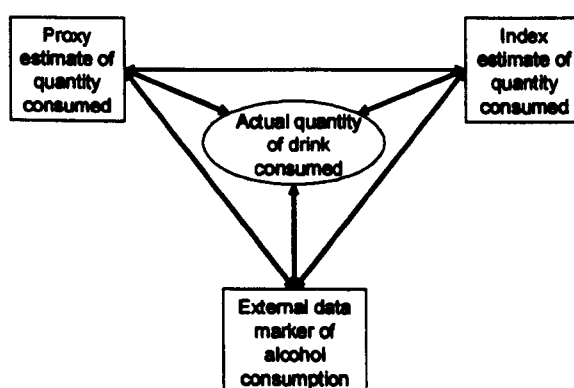
Where the subject of epidemiological research is unconscious, is unable to understand or respond to questions due to dementia or other illness<sup>(33)</sup>, has died, or is unable to respond for other reasons, it is sometimes not possible to obtain exposure information from the subject themselves. The use of secondary, or proxy, respondents as informants about the subject (the index) is one approach to addressing this problem. For example, many studies of Alzheimer's disease rely on proxy informants<sup>(5,12,25,34-43)</sup>, as indexes are considered unable to respond to questions reliably. Other circumstances where proxies are used include studies of some conditions among the elderly<sup>(6,14,17,26,28,44,45)</sup> or children<sup>(46-48)</sup> where, because of age or cognitive ability, the index may be unable to provide reliable responses. In all such situations, use of proxies to obtain data is necessary to ensure a representative sample of the study population<sup>(16)</sup>, or simply to obtain any data at all. Yet this raises the question of whether data obtained from proxy respondents is adequately reliable to be used either at an individual level, or on aggregate to determine exposure prevalence in study populations.

Of major importance in public health are two common subject areas, alcohol and tobacco use, which may be primary exposures, or confounders of other associations.

These areas may perform quite differently to one another with respect to the validity of proxy-reported data. The phenomenon of under-reporting, denial, in self-reported responses on alcohol consumption and alcohol problems in particular is well-documented, although non-differential misclassification and over-reporting<sup>(49,50)</sup> are also possible. It is important to acknowledge that over-reporting by indexes relative to proxies does not necessarily indicate that it is the proxy who is under-reporting – it may be that the index is over-reporting<sup>(49,51,52)</sup>. Conversely, in most societies smoking is not generally regarded as a taboo behaviour, especially among adult males, so reporting of tobacco use is likely to be free of some of the biases we would anticipate encountering with respect to alcohol reporting<sup>(49-51,53-57)</sup>. This is concordant with the consensus in the literature<sup>(19,21,23,24,27,58-66)</sup> as discussed in this chapter and later in this thesis. Questions arise regarding the way in which proxies perform in these, and over a wide range of other subject areas.

These are empirically testable issues. To take this question forward, one must assume there is a ‘true’ answer to every question posed. In theory, responses which reported this truth would provide the highest quality data and would be the ‘gold standard’. In practice, however, the truth may not be obtainable using a questionnaire, and the direction and magnitude of departure from the theoretical gold standard may vary according to the respondent asked. In order to assess proxy response quality, different comparative standards may be used. Proxy response quality can be assessed either by comparing proxy-provided data with index-provided data, using the index as the standard, or by comparing proxy-provided data with that obtained from an objective, external source, as illustrated by Figure 1.1.

**Figure 1.1** Comparing proxy reports, index reports and external data - the example of alcohol



The latter is discussed in the literature and is acknowledged as a reasonable method to validate proxy responses under certain conditions<sup>(53)</sup>. However, this chapter examines the former, while recognizing that indexes themselves may be fallible sources of data, and that in some situations the proxy might be the better data source.

### **1.3 Materials and methods**

A systematic literature review of studies that used proxy respondents to obtain some or all of their data on alcohol use, tobacco use and other subject areas was carried out. Databases searched were Web of science, Medline/Pubmed and Embase from the inception of the databases until 20<sup>th</sup> May 2006. Search terms were 'proxy', 'surrogate', 'next-of-kin' or 'informant'. Only papers written in English were included. Titles and abstracts of identified papers were inspected individually to assess whether they related to studies in humans, did not include only children, specifically evaluated quality of proxy respondents as an aim and explicitly quantified agreement between index and proxy responses using either Cohen's kappa for categorical data, or weighted kappa coefficient for ordinal data, or the intraclass correlation coefficient for continuous data. Papers using percentage agreement as their sole statistical method of evaluating agreement were excluded, since this common way of assessing agreement does not account for the role of chance and therefore cannot be used to compare across questions. Papers in which the number of index-proxy pairs was less than 50, and papers where the mode of interview (e.g. face to face, telephone) differed among proxies and indexes were also excluded.

The remaining papers were obtained. Data extracted from each study included statistical methods used to compare proxy and index responses, and the effect of the following on index-proxy agreement: index characteristics; proxy characteristics; proxy selection method; index-proxy relationship. Where kappa values were available, degree of agreement was classified in accordance with the scheme developed by Landis and Koch<sup>(67)</sup>: <0, poor; 0.00–0.20, slight; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; >0.8, almost perfect.

## **1.4 Results**

The initial inclusion terms yielded 2161 papers. 1615 were excluded based on the exclusion terms. A further 443 were excluded following inspection of titles and 71 more after inspection of abstracts, leaving 32 papers for detailed assessment. These papers are summarised in Table 1.2.

The majority of the 32 papers examined were based on cross-sectional surveys, with the remainder being case-control studies and one cohort study. Studies varied in size from 81 to 10011 index-proxy pairs, with larger studies tending to use telephone or self-administered questionnaires, and smaller studies using face to face interviews as the mode of data collection. Study subjects varied widely, including people with brain injury, Alzheimer's disease or dementia, men and women aged over 65 years, cancer patients and patients recovering from injuries, as well as some randomly selected population based samples. The choice of also proxy varied between studies, with some only considering specific proxy types (e.g. spouse, next of kin), some using index-nominated proxies or caregivers, and others using whoever was available. As described above, only studies using Cohen's kappa coefficient or ICC were considered, however it was noted that only one third of the eligible studies calculated precision estimates for these parameters. Some studies detailed procedures taken to avoid data contamination, which is potentially caused when index and proxy respondents have the opportunity to communicate with one another and possibly discuss their responses between interviews which may then influence responses given by the second respondent. However, many did not provide this level of detail.

### **1.4.1 Alcohol**

The literature on proxy-reported alcohol consumption is wide-ranging and findings by different investigators are largely complimentary<sup>(5,7,10,24,27)</sup>. The key findings are summarised in Table 1.1. Broad indicators of alcohol consumption (average frequency, average number of drinks per occasion) show almost perfect index-proxy agreement when classified into ordinal categories<sup>(5,7,24)</sup>, and alcohol consumption status (yes/no) shows substantial agreement<sup>(27)</sup>. Composite measures of daily alcohol consumption (grams) show only moderate agreement<sup>(24)</sup> with considerable variability between pairs at the individual level<sup>(7)</sup>. Reliability may vary according to alcohol

type: there is a suggestion it is highest for wine but only moderate for beer and hard liquor, although this could reflect differences in drinks consumed inside and outside the home, and thus whether they are directly observable by the proxy<sup>(24)</sup>. There is a suggestion that agreement for binge- and heavy drinking is moderate/good<sup>(24)</sup>.

#### 1.4.2 Tobacco use

There was a consensus in the literature regarding index-proxy agreement on cigarette use<sup>(5,10,23,24,27)</sup>, whereby agreement depends on the required level of detail: whereby there is 'good' to 'excellent' agreement about general cigarette-use (current/non/ex-smoker)<sup>(23,24,27)</sup>, but 'poor' agreement for more detailed information, such as brand smoked and number of years of smoking. There is no clear consensus when examining agreement on amount. Some authors suggest that detail beyond that required to calculate pack-years is hard to obtain<sup>(24)</sup>, whilst others found agreement for current amount to be almost perfect<sup>(5,27)</sup>. This lack of consensus may be due to the wide range of data collection methods and study settings which addressed this subject area. The key findings are summarised in Table 1.1.

**Table 1.1** Key findings related to index-proxy agreement on alcohol and tobacco use

Study details	Study Design	Comment
Demissee, S. et al 2001 <sup>(5)</sup>	Cross sectional survey. Self-administered questionnaire carried out by non-demented Alzheimer sufferers (index) compared with two proxies. n=81	Observed 'almost perfect' agreement on overall smoking behaviour (kappa = 0.87). Observed 'substantial' agreement on overall alcohol use (kappa = 0.74).
Graham, P. and Jackson, R. 1993 <sup>(7)</sup>	Men and women aged 25-64 who were representative sample of myocardial infarction controls and small number of cases from a larger case control study interviewed face to face. Closest next of kin (proxies) interviewed 6-8 later. n=514.	Found no evidence that proxies systematically over- or under-reported drinking frequency (kappa = 0.79 among cases, 0.80 among controls)
Hatch, M.C. et al 1991 <sup>(10)</sup>	Cross-sectional survey of prenatal patients recruited from obstetric services and their spouses/partners. n=136.	Found evidence of considerable misclassification with respect to alcohol use even though statistics sometimes indicated good index-proxy agreement. Found agreement on smoking behaviour to be high (Private patients: kappa = 0.84 for first trimester smoking, 0.95 for current smoking; public patients 0.84, 1.00 respectively)
Navarro, A.M. 1999 <sup>(23)</sup>	Cross-sectional survey. Of adults randomly selected. Index and proxy completed detailed interview by telephone (n=10011)	High agreement on smoking status between index and proxy (kappa = 0.76-0.91), although this differed by ethnic group
Nelson, L.M. et al 1994 <sup>(24)</sup>	Case control, interviewer-administered interviews of all controls and their proxies and where possible of cases and their proxies from case-control study of spontaneous subarachnoid haemorrhage. n=283 (control pairs), 68 (case pairs)	Alcohol consumption showed varying range of agreement depending on measure. Lowest agreement was for grams per day (kappa = 0.52). Highest agreement was for amount of drinks per occasion (kappa = 0.83) and frequency of drinking (kappa = 0.82). Cigarette smoking history showed very high agreement (kappa = 0.79 - 0.93)
Passaro, K.T. et al 1997 <sup>(27)</sup>	Cross sectional study of pregnant women. Index and spouse (proxy) both completed self-administered questionnaire. N=8414.	Kappa coefficient for drinking status showed 'substantial' agreement (kappa = 0.74). Kappa coefficient for smoking status 'almost perfect' (kappa = 0.90)

### 1.4.3 Other subject areas

Proxies tend to be good informants for easily observable socio-demographic characteristics including marital status, education and for body habitus measurements<sup>(10,24)</sup>. Although there is an extensive literature examining proxy responses in studies of occupational exposures (e.g. asbestos), no studies met the inclusion criteria employed here. There is, however, a suggestion that responses are more accurate when asking about current rather than past occupational exposures.



There is a lack of consensus regarding the extent of index-proxy agreement among ten studies addressing reports on physical health and symptoms<sup>(5,6,9,14,16,17,24-26,31)</sup>. There was a tendency for proxies to display moderate or better agreement when reporting overall health and easily observable, especially ‘chronic physical’ conditions, and for visible and unambiguous medical history items (e.g. diabetes, amputation). Agreement is lowest for conditions that are either private or very general. Agreement is generally higher for physical activities of daily living (PADL) than for instrumental activities of daily living (IADL). The former tend to be more easily observable and less subjective than IADL<sup>(31)</sup>.

Five reviewed studies addressed psychological state<sup>(2,6,16,17,25)</sup>. There was a consensus that index-proxy agreement was only fair for emotional states and emotional and nervous conditions and psychological well-being, since these feelings tend to be private and not well-known by proxies<sup>(16,17)</sup>. Observable facets of social networks and social interaction are well-judged by proxies. As might be expected however, proxies are poor judges of perceived emotional support<sup>(3)</sup>. Life events are often used as indicators of exposure to stress; agreement is substantial for public and observable (e.g. death of a parent), and lower for other (e.g. serious illness of a spouse), life events<sup>(3)</sup>. There is a suggestion that proxies are not able to accurately capture a patient’s own perception of their quality of life and tend towards underestimation<sup>(25)</sup>.

Only two studies were identified addressing physical activity<sup>(8,24)</sup>: little information is available on physical activity as such data tend to be collected on healthy subjects, a group that do not require proxy respondents. The available literature indicates that broad indicators of physical activity level (PAL) show very good, whilst detailed aspects show only moderate agreement<sup>(24)</sup>. Substantial agreement for both leisure and work-time activity was reported, using 3-point scale<sup>(8)</sup>.

#### 1.4.4 Index and proxy attributes

Nine reviewed papers identified specific index attributes and were largely in agreement in their assessment of how these affected proxy response quality<sup>(7-9,16,18,19,22,26,29)</sup>. No difference in quality of response was found by index’s age or sex<sup>(8)</sup>, nor did there tend to be any difference in either quality of response or response rate by case-control status<sup>(7,9,18,19,22,26)</sup>, other than when the examined condition was

difficult to observe (e.g. back pain)<sup>(9)</sup>. Due to the impossibility of comparing any proxy response with the ‘true’ subject response, the above findings should not be generalised to studies where the index has died.

Fourteen papers assessed the quality of proxy responses obtained<sup>(1,4-10,14,16,19,20,29,33)</sup> according to proxy age and sex, and the index-proxy relationship. Most studies agreed that spouses provide highest-quality data and highest response rate, but there is no clear consensus on the optimal order of relationship beyond that<sup>(5,7,10,14,19,24)</sup>, and several studies have found little effect of relationship type of relationship on agreement level<sup>(7,20,29)</sup>. It is reported elsewhere to be the quality and nature, rather than formal relationship (e.g. spouse, sister etc), which most affects the proxy response quality<sup>(9,15,16,20,26)</sup>. Depending on question content, the proxy attributes age and gender have been found to affect response quality<sup>(5,8,20,33)</sup>.

There is consensus in the literature that caregiver proxies overestimate disability and underestimate index’s independence, function and quality of life, and that the extent of index-proxy disagreement increases with increased caregiving burden<sup>(1,4,14)</sup>.

#### 1.4.5 Question style

Ten identified papers focused on the effect of the way in which questions are asked on proxy data quality<sup>(4,8,14,16,17,22,29,31,33,68)</sup>. There was a consensus that broader categories and reduced detail in question design increase agreement<sup>(4,16,22,31,33)</sup>, and questions requiring a yes/no answer or that assess concrete, observable information show better agreement than questions requiring judgement, opinion, firsthand experience of activities outside the home, or the proxy’s subjective perception. Agreement is also reported to be highest for recent exposures<sup>(22,29)</sup>. Mode of interview appears to affect response quality: agreement in telephone interviews tends to be lower than in face-to-face interviews, although this is difficult to interpret as a number of other factors vary between studies that use different modes of interview. No study was identified here that explicitly set out to evaluate the agreement using different interview methods.

#### 1.4.6 Response rates

Response rates differ between proxy and index respondents, due to different exposure knowledge and altered motivation<sup>(64,69)</sup>: missingness is often greater for proxy than index responses<sup>(5,6,20)</sup>. This has implications for study power due to smaller sample sizes<sup>(64,69)</sup>, and may lead to biased effect measures depending on the reasons influencing non-response.

There is some evidence that non-response rate may be affected by choice of proxy, with the highest response rate observed when spouses are proxies and lower rates observed for distant relatives and friends compared with first degree relatives<sup>(5,6,8,20,70)</sup>.

In case-control studies, proxy response rates may differ between groups also leading to biased effect measures. However, Poulter *et al* found mainly non-significant differences in the proportion of 'don't know' responses between case and control proxies in a case-control study examining reliability of data from proxy respondents, and found little difference in recall bias<sup>(29)</sup>. Non-response is dependent on both the proxy-index relationship and on the type of questions asked<sup>(5,6,32,33,64)</sup>.

### 1.5 Discussion

This chapter provides a thorough evaluation of the available research investigating the reliability of proxy respondents in observational studies. The issues explored here have previously been the subject of three overviews<sup>(33,71,72)</sup>, but none was exhaustive: Sprangers and Aaronson<sup>(72)</sup> concentrated on the use of health care providers as proxies in evaluating quality of life among patients with chronic disease; Neumann *et al*<sup>(71)</sup> reviewed the validity of care providers and 'significant others' as proxy respondents in studies of adults aged 60 and older, in 24 studies investigating functioning, physical health, cognitive status and psychological well-being; Nelson *et al*<sup>(33)</sup> provide an overview of the impact of proxy-provided information on the exposure-disease association in epidemiologic research, but their paper was a theoretical discussion of the issue rather than a literature review. The current chapter is a comprehensive review of the literature comparing proxy to index responses to surveys, which confirms the findings of the previous three overviews, whilst

additionally investigating all types of proxy respondent, index subject and study question.

There are several limitations inherent in examination of this range of studies. Methods of information collection from respondents were not always internally consistent. In some studies, index and proxy separately undertook an interviewer-administered questionnaire within a short time period, with the same interviewer. This is the ideal data collection method for ensuring data comparability, since little opportunity arises for data contamination between interviews. However, elsewhere there was a lengthy delay between interviews allowing ample opportunity for data contamination. Additionally, the literature reviewed is very heterogeneous with respect to study design and methods, characteristics of indexes and proxies and the exposures and outcomes being investigated. Consequently, comparisons are often difficult. Despite these limitations, some clear conclusions emerge.

The quality of responses obtained from proxies in observational studies is variable, depending on factors relating to the content and style of the question. Alcohol use elicits a wide range of index-proxy agreement depending on the specific context and question. Agreement tends to be highest where questions focus on broad indicators of alcohol consumption (e.g. average frequency of drinking alcohol) rather than detailed information, and in general appears to be highest for questions about wine and lower for other alcohol types. Questions asking about comparatively observable measures of alcohol consumption also elicit better agreement than those asking about behaviours which are difficult for a proxy to observe (e.g. alcohol consumption outside the home). It is important to note that these findings cannot be generalised to very heavy drinkers, since such individuals tend to not respond to surveys or even be identified within target populations, and hence the behaviour of this extreme group is not usually captured in observational studies. Contrastingly, tobacco use is almost uniformly well-reported by proxies with respect to index reports, provided questions again focus on easily observable aspects of this behaviour (e.g. brand smoked) rather than attempting to obtain detailed information such as number of cigarettes smoked per day. Assessment of psychological state is fairly unreliable. This is expected since, while a proxy may be able to infer certain things from observed behaviour, it is

impossible to have reliable knowledge of the index's internal state of mind. This is, however, the only area where reliability is consistently poor.

In general, proxy responses agree more closely with index responses when the question addresses easily observable, objective measures or where the subject matter is not embarrassing or awkward. Questions asked using broad yet clearly defined categories, without seeking high levels of detail, tend to elicit greater agreement. Greater agreement is also achieved when questions are asked face-to-face by a trained interviewer, rather than by telephone or via a self-administered questionnaire. These findings are supported by the results investigating specific question content, which consistently showed that questions asked on recent or current, less detailed and more easily observable exposures elicit higher agreement than more detailed questions, or those addressing past exposures.

The quality of responses obtained from proxies in observational studies also varies according to characteristics of the proxy. There is a general consensus in the literature is that spouses provide most reliable proxy data and yield the highest response rate. These findings suggest that it may be relationship quality, such as the amount of time regularly spent together or number of years the index and proxy have known one another, rather than formal relationship (e.g. spouse, daughter), which has greater impact on quality of responses. The evidence presented here shows that reliability also diminishes as caregiver burden increases. This further indicates the importance of the state of mind of the proxy themselves in the accuracy of their responses – it may be hypothesized that the increased burden falling on caregivers renders them liable to overestimate incapacity through heightened awareness of the index's problems.

The extant literature is inconclusive regarding direction of misclassification of proxy responses in comparison to index responses. Random, or non-differential misclassification may be greater for proxy than index respondents, leading to precision loss, although odds ratios computed using either proxy or index data where misclassification is non-differential are similar in magnitude<sup>(7,24,43)</sup>. However, proxies may systematically over- or under-report exposure information compared with indexes, both of which would lead to biased estimates of exposure prevalence<sup>(16,24,43)</sup>; systematic over-reporting would lead to over-estimation of effect measures in cross-

sectional surveys, whilst in studies employing a comparison group, the direction of proxy exposure misclassification may differ between groups resulting in gross over- or under-estimation of the effect measure, i.e. if proxies for cases in a case-control study tend to over-report exposure whilst proxies for controls tend to under-report, the resulting odds ratio for the effect of the exposure on outcome will be substantially biased towards overestimation. Evidence presented here indicates that case-control status seems unrelated to proxy reporting bias, suggesting that effect measures obtained when using proxies for cases or controls would be unbiased. However, the very limited evidence in this area limits the possibility of drawing firm conclusions in this matter. Future research would greatly benefit from a quantitative investigation into the extent of bias introduced into estimates of measures of effect when using proxy respondents. In the specific situation that the case has died, there is very little literature describing extent of misclassification, and it is not possible to generalize other study findings to this extremely specific situation.

Several researchers argue that proxies provide reasonable data. Demissee et al<sup>(5)</sup>, describing reliability of proxy information collected in family studies of Alzheimer's disease concluded that the 'study supports the reliability of proxy responses for most categories of questions that are elicited in typical epidemiological studies'. Others have identified question categories where proxy use is inappropriate. For example, in assessment of internal psychological states such as pain, anxiety and self-assessed quality of life, by definition the answer must be given by the index. Magaziner et al<sup>(16)</sup> observed proxies to be poor judges of perceived emotional support: a proxy can offer their opinion of the index's internal psychological states, but their response answers a different question. It must be accepted that such questions cannot be addressed when the index is unable to respond.

In summary, therefore, proxy informants can be a useful source of information in observational epidemiology where the index, is unable for whatever reason to provide information about him or herself. The reliability of that information is considerably greater where that being asked about is directly observable and where the proxy is in a position to observe it.

**Table 1.2** *Studies addressing the use of proxy respondents*

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Clarridge, B.R. and Massagli, M.P., 1989 <sup>(1)</sup>	Cross-sectional survey investigating the agreement between index and female proxy of 22 health complaints, interviews conducted by telephone	408	Comparison of index and proxy reports of 22 health complaints	Random sample of men living in Wisconsin, 1984	Female living in the same household	Y		Agreement varied according to the persistence of the health complaint. Proxy underreporting was sizeable for all variables but varied by symptom. Highest agreement was observed for easily observable complaints including arthritis (kappa=0.63), allergy (kappa=0.67), ear/hearing problem (kappa=0.56), rash (kappa=0.60). Agreement was moderate (0.41 < kappa < 0.60) for a range of other complaints including cold, cough, sinus trouble, backache, knee problem and chest pain. Agreement was lowest depression (kappa=0.06).
Conner, K.R., et al 2001a <sup>(2)</sup>	Cross sectional survey. Structured interview of index and their proxy.	80	Assessment of stressful life event, social support and suicidal behaviour	Psychiatric in-patients aged 50-91 who attempted suicide	Mainly women, including spouses, partners, children, other relatives, friends and caregivers	Y		'Good' agreement for social interaction (ICC=0.61), but not for perceived emotional support (ICC=0.28). When examining life events, agreement was substantial for public and observable events (death of a parent, child, sibling or spouse', kappa=0.70, employment/business disruption, kappa=0.61), but lower for more ambiguous events ('disruption of spousal relationships', kappa=0.48, 'serious illness of parent, child, sibling or spouse', kappa=0.38)
Conner, K.R., et al 2001b <sup>(2)</sup>	Cross sectional survey. Structured interview of index and their proxy.	80	Assessment of psychiatric diagnosis	Psychiatric in-patients aged 50-91 who attempted suicide	Mainly women, including spouses, partners, children, other relatives, friends and caregivers	Y		Agreement substantial for dependence (kappa=1), but poor for substance abuse disorders (values not reported)

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Cusick, C.P. et al 2000 <sup>(4)</sup>	Cross-sectional study involving three outcome measures, including a questionnaire administered by telephone by trained interviewers.	204	Comparison of index and proxy reports of functional ability of index	People with traumatic brain injury aged 14-82, who had been discharged from hospital between 6 months and 5 years before study	Self-selected, various types		Y	Strongest agreement observed among groups questions assessing concrete, observable information (physical independence: ICC=0.70, cognitive: ICC=0.68, home integration: ICC=0.79, productivity: ICC=0.84). Agreement poor in the opposite circumstances: ICC<0.3 for areas that required judgement, opinion, firsthand experience of activities outside the home setting, or rater's subjective perception. Self-selected proxy found to provide reliable data for many outcomes, suggesting that when proxy is selected by index, there is non-differential misclassification.
Demissee, S. et al 2001 <sup>(5)</sup>	Cross sectional survey. Self-administered questionnaire carried out by index and two proxies	81 indexes, 159 proxies	Assessment of medical history, medication use, health behaviour and cognitive ability	Non-demented Alzheimer sufferers	2 per index, both self-selected	Y	Y	High non-response rate when proxies asked about medication history. Overall agreement almost perfect for diabetes and heart disease, substantial for thyroid disease, hypertension, cancer and arthritis and moderate for head injury. Overall agreement on smoking almost perfect when comparing reports of pack-years (the average number of packets of cigarettes smoked per year multiplied by number of years smoking (1, 26)) (ICC=0.90). Substantial agreement found for alcohol consumption (number of drinks usually consumed) at ages 16-39 and 40-64 (kappa=0.62 and 0.71), but only fair agreement for consumption at age 65 and older (kappa = 0.31). Substantial agreement on amount of alcohol consumed at three stages of life (ICC=0.64). Found slight differences in the ability of different family members to reliably report on smoking and alcohol consumption. Male proxies demonstrated almost perfect agreement, whilst female proxies demonstrated only substantial agreement for alcohol consumption. Sons and spouses as proxies provided almost perfect information on both smoking and alcohol consumption, whilst daughters provided only substantial agreement on these. Authors recommend that sibs, particularly sisters, are the second ablest respondents. Also observed that spouses were able to provide information more often than other proxy informants



Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Farrow, D.C. and Samet, J.M. 1990 (6)	Cross sectional survey. In-person interview of index and abbreviated interview of proxy	622	Comparison of index and proxy responses to questions on index's health status, major life events, social network and functional status	Elderly cancer patients, 65 years or older	Spouse if available, then friend, adult relative or child	Y	Y	Overall agreement ranged widely ( $\kappa = 0.33-0.67$ ). For medical conditions, including high blood pressure, heart problems, bronchitis/emphysema, asthma, agreement was usually moderate ( $\kappa > 0.61$ ) or almost perfect ( $\kappa > 0.8$ ) diabetes, when reported by spouses. Agreement was almost perfect for easily observable major life events when reported by spouses (moved during year prior to diagnosis, $\kappa = 0.85$ , number of children visited at least monthly, $\kappa = 0.89$ ), but much lower for questions about social contact when reported by any respondent and was either moderate or almost perfect when reported by child/friend proxies. Agreement was especially low for Duke subscales such as perceived health or social health. Agreement inconsistent for questions on social network and major life events. Agreement higher when factual information solicited rather than personal information or attitudes, and almost always higher when spouse was the respondent, rather than child or friend. Lowest non-response rate observed among spouses as proxies
Graham, P. and Jackson, R. 1993 (7)	Cross sectional survey. Indexes interviewed at single study centre. Proxies interviewed within 6-8 weeks at respondents home. All questionnaires administered by one of three interviewers.	514	Comparison of index and proxy reports of index alcohol consumption frequency	Men and women aged 25-64 who were a representative sample of myocardial infarction controls (n=456) and small number of cases (n=58) from wider case-control study	Closest next-of-kin	Y	Y	Very good agreement for amount of alcohol consumed, although lower among case-proxy pairs (mean difference - 2.25g/day) than control-proxy pairs (mean difference - 0.77g/day). Considerable variability was observed between individual pairs in the level of agreement. Exact agreement 'almost perfect' for cases, and very high in the 'substantial' range for controls ( $\kappa = 0.80, 0.79$ respectively) when examining 5 categories of alcohol consumption frequency. Findings cannot be generalised to very heavy drinkers. Age and sex of primary respondent and relation of proxy to the primary respondent were unrelated to the magnitude of primary-proxy differences.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Graham, P. and Jackson, R. 2000 (6)	Analysis of data from study that collected information on habitual physical activity from primary participants and next of kin. Indexes interviewed face to face using structured questionnaire, proxies interviewed 6-8 weeks later using identical questionnaire and same interviewers.	456	Comparison of reports of habitual physical activity by index and proxy	Controls in Auckland Heart Study, a community-based case control study of coronary heart disease	Next of kin, usually spouse	Y	Y	On a simple 3 point scale, agreement was substantial for index-proxy reports of physical activity in leisure time ( $\kappa=0.66$ ) and work time ( $\kappa=0.62$ ), with a tendency for proxies to under-report relative to the index. Found no evidence to prefer spouse proxies when collecting information on work time physical activity.
Halabi, S. et al 1992 (9)	Case control. Face to face interviews carried out with cases and their proxies and controls and their proxies. Physical examination carried out on all indexes to confirm presence/absence of disease	100 case/proxy pairs, 100 control/proxy pairs	Reports of heart disease, back pain, rheumatoid arthritis, hypertension or pulmonary disease	Adults from a sample of screened households reporting themselves to have one of 5 chronic diseases	Spouse if available, otherwise randomly selected household member	Y	Y	Level of agreement varies between conditions, and for case-proxy versus control-proxy pairs. Agreement best for heart disease: substantial for cases (0.79), almost perfect for controls (1.00). Agreement for hypertension substantial for cases, (0.65), fair for controls (0.50). Agreement for back pain fair for both cases and controls (0.49, 0.50 respectively). Agreement for number of cigarettes smoked per day fair for both cases and controls (0.60, 0.54 respectively). Results suggest that health interview surveys are accurate for data collection of well defined chronic conditions. Members of the same household were found to be good proxy informants, regardless of specific relationship

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Hatch, M.C. et al 1991 <sup>(10)</sup>	Cross-sectional survey of prenatal patients and their spouses/partners.	136	Spouse/partner's occupation, smoking and drinking	Women recruited from obstetric services and their spouse/partner	N/a - the index-proxy agreement was examined in both directions	Y		Almost perfect agreement on work status. Up to 98% agreement on index's current occupation. Agreement on smoking status was very high (kappa = 0.84-1.00). Agreement on amount smoked more variable, ranging from kappa=0.52 for men's reports on women recruited from public clinics, to 0.83 for reports by women recruited from private clinics on men. Good agreement on drinking status (current drinker: yes/no) and amount of alcohol drunk (<1 drink versus ≥1 drink), although evidence of considerable misclassification among pairs recruited from public clinics
Herrmann N 1985 <sup>(11)</sup>	Cross-sectional survey comparing and medical, smoking and dietary consumption data as reported in face-to-face interview or self-completed questionnaire by cases/controls in a case-control study of colon cancer and their next-of-kin. Both members of a pair reported data using the same mode.	191 case-proxy pairs, 192 control-proxy pairs	Agreement between index and proxy reports of medical, smoking and dietary consumption data	White adults, male and female, aged 45-69 years, cases and controls from a study of colon cancer	Next of kin, priority order spouse, child over 25 in the same household, other adult over 25 years in same household, friend or relative living within 20 miles	Y		Medical and cigarette smoking variables had at least substantial agreement (kappa>0.6) for 54% of comparisons. Diet histories were more variable in agreement, with kappas ranging from 0.17 to 0.59 (slight to fair). No difference was observed between when the proxy was husband or wife. Agreement was always substantially higher when mode of interview was face-to-face rather than self-completed questionnaire. E.g. For medical history items as reported by case and wife, overall agreement was substantial when interviews were conducted (kappa=0.67) and fair when self-completed questionnaires were used (kappa=0.42).

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Kukull, W.A. et al 1995 (12)	Case-control study based in Seattle investigating whether history of organic solvent exposure is associated with increased risk of Alzheimer's disease in people aged 60 or over. Information on solvent exposure collected in face-to-face interviews by a trained interviewer from cases, controls and control proxies	243	Agreement between controls and proxies on exposure to named organic solvents.	Control subjects, frequency-matched to cases with probable Alzheimer's disease on age and sex	Spouse, child, sibling or other	Y		Substantial agreement between control proxy and control responses to solvent exposure and probable solvent exposure: kappa = 0.64, 0.73 respectively.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Lien N 2001 (13)	Cross-sectional study using data from the Norwegian Longitudinal Health Behaviour Study. Proxies: self-completed questionnaires carried out at school at baseline, sent by mail at follow-up. Indexes: self-completed questionnaires.	924 children, 648 mothers, 735 fathers, various sets of pairings compared.	Index-proxy agreement on parental education and SES, based on occupation. Comparison made between parental baseline reports and adolescent baseline reports, and between parental baseline reports and adolescent follow-up reports.	Population-based sample of Norwegian parents	Children of index, young adolescents	Y		Agreement on SES, based on occupation, substantial ( $\kappa > 0.61$ ) or almost perfect ( $\kappa > 0.8$ ) for all categories of derived variable, both at proxy baseline and follow-up, for both parents. Agreement slightly stronger with fathers than with mothers in all instances, and agreement slightly stronger at follow-up in all instances than at baseline, although these differences were small.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Long, K. et al 1998 <sup>(14)</sup>	Cross-sectional survey. Telephone interviews of indexes and their proxies.	340	Assessment of index's functional status and medical history	People aged 65 and older	Index's caregiver	Y		Very wide range of kappa values with respect to medical history items. Highest concordance for visible and unambiguous conditions. Observed increased index-proxy agreement when the issues being addressed were readily observable. Percentage agreement for difficulty of carrying out some activities of daily living ranged were as high as 99.7% (kappa=0.856) for 'toileting' - although some categories elicited much lower agreement, e.g. bathing, kappa = 0.17 - with an overall kappa for ADL of 0.66. Agreement on medical history was sometimes as low as 78%, although kappas ranged widely from 'slight' for Alzheimer's (kappa = 0.28) to 'almost perfect' for easily the observable medical items diabetes (kappa=0.85) and amputation (0.83). An association was observed between the index-proxy relationship and the extent of medical history agreement. The self-reported burden of the caregiver was associated with the extent to which they overestimated the disability of the index.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Magaziner, J. et al 1988 <sup>(15)</sup>	cross-sectional study. Interviewer administered questionnaire given within 1 week of hospital admission. Shorter questionnaire administered to patient proxy.	361	Index-proxy agreement on items pertaining to patients' pre-fracture health and functional status	Hip-fracture patients aged 65 and older	Interviewer -identified. Most are first degree relatives and/or frequent visitor	Y		Proxies who report the greatest contact with patients tend to demonstrate the greatest agreement. However, when they do disagree, they tend to overestimate patient disability. Provision of care enhanced index-proxy agreement, perhaps by providing greater sensitivity to an individual's needs. Uniformly low agreement on health symptoms (kappa: 0.24 - 0.59) but substantial to almost perfect agreement (kappa>0.6) for 5/9 chronic health conditions (only slight to moderate agreement (kappa<0.6) observed for the other 4).  Agreement lowest for relatively private or very general conditions. Agreement highest for easily observable, well defined health symptoms but particularly poor for generalised aches and pains. Relatively poor agreement for emotional or nervous conditions (kappa<0.4). No general pattern of agreement and bias by proxy characteristics identified.  Agreement for PADL items was poor for 7 measures (kappa<0.4), moderate for 6 (kappa 0.4-0.6) and substantial for only 1 (kappa>0.6). Agreement for summary measures for both PADL and IADL higher than individual measures. Agreement low (corresponds to kappa<0.4) for emotional states, since these feelings tend to be private and not well known by proxies.  Overall, agreement is generally higher for summary measures than individual measures. ICC for three summary measures of physical functioning are 0.68, 0.56, 0.65 as compared with kappa<0.6 for 6/15 individual PADL items, and 0.4<kappa<0.6 for a further 7/15. This is expected, since random errors associated with individual items are dampened by combining items.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Magaziner, J. et al 1996 <sup>(16)</sup>	Health survey. Face to face interviews carried out with indexes, and with proxies 3 weeks later.	538	Assessment of index's physical health and physical and instrumental functioning	Women aged 65 years and older, participating in the third home interview of the health survey	Self-selected	Y	Y	Substantial to almost perfect agreement for most physical activities of daily living (PADL) and for all instrumental activities of daily living (IADL) ( $\kappa > 0.6$ ). Almost perfect agreement observed for some easily observable chronic conditions (diabetes, $\kappa = 0.86$ ; thyroid or other glandular disorders, $\kappa = 0.74$ ; heart trouble, $\kappa = 0.76$ ). Observed that proxies are more likely to report the presence of, or to over-report the level of a condition, symptom or functional problem than indexes. Proxies living with the index demonstrate better agreement for chronic conditions, physical symptoms and PADL. Among proxies not living with the index, those who visited the index more frequently demonstrated greater agreement for physical symptoms, PADL and IADL.
Magaziner, J. et al 1997 <sup>(17)</sup>	Cross sectional study. Indexes interviewed at place of residence, proxies interviewed by phone within 1 month.	233	Assessment of functional status	Patients aged 65 years or older participating in 12 month follow-up study of hip fracture recovery	Self-selected	Y	Y	Agreement highest for a easily observable measures of independence of instrumental functioning (handling money, $\kappa = 0.81$ ; taking medications, $\kappa = 0.81$ ), and lower for less easily observable measures of dependence of physical activities of daily living (taking a shower, bath or sponge bath, $\kappa = 0.18$ ; climbing five stairs, $\kappa = 0.18$ ). Agreement lowest for a subjective measure of depression ( $ICC = 0.38$ ). Proxies tend to report more disability than indexes.



Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Marshall et al 1980 <sup>(16)</sup>	Cross-sectional survey to compare dietary reporting by men and by their spouse-proxies, within a larger study investigating the association between ingestion of a number of food items and cancer of the stomach, bowel and mouth. Extensive interviews carried out separately with index and proxy by college-educated lay interviewers. The spouse was conducted privately, within 2-16 weeks after the index interview.	158 (67 cases, 91 controls)	Comparison of reporting frequency of ingestion of a wide variety of food items by indexes and proxies	Male cases and controls within a study investigating the association between diet and cancer	Spouses	Y		Agreement varied widely. Percentage agreement tended to be slightly lower among case-spouse than control-spouse pairs; many cases were sick at the time of interview and were asked to recall an earlier period. Whilst percentage agreement tended to be high - above 75% - agreement adjusted for chance was generally in the 'fair' range - $0.2 < \kappa < 0.4$ , or the low end of the moderate range. The authors conclude that dietary histories are not precisely replicable, but may reveal gross differences between cases and controls.
McLaughlin, J.K. et al, 1990 <sup>(19)</sup>	Resurvey of previous case-control study subjects and their next of kin using face to face interviews; comparison of original responses and next-of-kin reinterview responses	108	Index-proxy agreement on cigarette smoking, coffee drinking and alcohol beverage intake	Cases: newly diagnosed with renal cancer. Controls: population based	Next of kin	Y		All types of respondent provided almost perfect agreement with original index response with respect to smoking status ( $\kappa > 0.89$ ). Agreement was lower for usual number of cigarettes smoked per day with 'other' respondents providing worst agreement for nonfilter cigarettes, filter cigarettes and pack years ( $\kappa = 0.13, 0.45$ and $0.20$ respectively) whilst spouses provided much better agreement, moderate for nonfilter cigarettes and pack years ( $0.53; 0.59$ ), fair for filter cigarettes ( $0.39$ ). Next of kin responders, particularly spouses, provide reliable answers about smoking exposure of deceased relatives about as reliably as living individuals when reinterviewed. They are particularly accurate with respect to smoking status.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Medical Research Council Cognitive Function and Ageing Study 2000 <sup>(20)</sup>	Subsample of cohort study subjects for whom index and proxy baseline data was collected on a variety of health outcomes in UK subjects aged >65 years. Ultimately subjects were reinterviewed 2 years later to determine dementia and cognitive decline incidence. Interviews carried out either face to face or by telephone: this varied within some pairs - details not given in paper	1898	Proxy-index agreement on 18 health outcomes relating to past or present illness	People in 6 UK centres aged 65 or older	Nominated by index	Y		Results presented pictorially, showing mutually adjusted point estimates and confidence intervals for each factor in models examining agreement, bias and response rate. Few individual kappa values reported. However, results show numerically that type of relationship and length of time index-proxy have known each other do not predict agreement; female informants (either index or proxy) increase agreement above the mutually adjusted kappa = 0.66; older proxies (>85) and those not living with index decrease agreement from this value. Telephone interviews also lead to lower agreement. When examining proxy under-reporting relative to index, female/older proxies more likely to under-report, those not co-resident less likely to under-report. Interview modality did not appear important. Friends more likely not to respond, siblings and 'other' proxies, as well as those not co-resident more likely to say they did not know. Sex of neither proxy nor index was important for response rate.
Metzner, H.L. et al, 1989 <sup>(21)</sup>	Cross-sectional survey assessing husband-wife agreement on a variety of consumption and smoking behaviours. Both husband and wife interviewed face to face, within the Tecumseh Diet Methodology Study.	180	Index-proxy agreement in reporting frequencies of individual foods and food groups	Both husband and wife, aged 45-65, within married couples	Other spouse	Y		Agreement found to vary widely at the individual level, ranging from 0.11-0.92, being greatest for alcoholic beverages (kappa ranged from 0.70-0.92, substantial to almost perfect agreement). Low agreement found for many food questions, with kappa as low as 0.19. Overall, wives provided better agreement for husband self-report than husbands did for their wives (kappa=0.53 versus 0.42)

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Mills, K.M. et al 2000 (2)	Cross-sectional survey. Both members of couples who were either married or living together independently and simultaneously interviewed by trained interviewers. (n=92)	92	Proxy-index agreement on exposure to 37 household appliances	Married/cohabiting residents of two cities in California, aged 20-79, English-speaking	Partner of index	Y	Y	Agreement was quite good for presence/absence of exposure (kappa = 0.41-0.71 ) but only 'fair' reliability when considering hours of exposure (kappa = 0.23-0.56). Authors concluded that results raised serious questions about usefulness of proxies in case-control studies that require detailed exposure information. Agreement was found to be lower with increased recall time but, 'very good' proxy reports of concrete, well-defined exposures for recent time periods were observed.
Navarro, A.M. 1999 (2)	Cross-sectional survey. Index and proxy completed detailed interview by telephone (n=10011)	10011	Comparison of index and proxy report of smoking status, behaviour and attitudes, by ethnicity	Adults randomly selected as participants in California Tobacco Survey by random digit dialling	Household member aged 18 years or older	Y	Y	Found high agreement when investigating smoking status to be high and vary by ethnic group: kappa = 0.76 (Hispanics), 0.91 (Non-Hispanic whites), 0.91 (African Americans) and 0.82 (Asian Americans). Hypothesised agreement to be higher in smaller households than large households - a possible confounding factor in the above association - a proposal which could possibly be extended to a wide variety of exposures.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Nelson, L.M. et al 1994 (24)	Case control, interviewer-administered interviews of all controls and their proxies and where possible of cases and their proxies.	283 control/proxy pairs, 68 case/proxy pairs	Spontaneous subarachnoid haemorrhage	Live cases, healthy controls from a case-control study	Various, recruited in following order of preference: spouse, sibling, son/daughter, parent, other relative, friend.	Y	Y	Almost perfect agreement overall (0.86-0.99%), although a tendency to under-report weight and BMI observed. Perfect or near-perfect agreement for demographic characteristics such as marital status and education (kappa >0.8). Low agreement for questions on medications and hormone preparations (kappa = 0.52-0.82) Very good agreement for broad indicators of physical activity level (PAL). Only moderate agreement for detailed aspects of PAL (kappa = 0.57-0.67). Smoking history information agreement substantial to almost perfect in all aspects (kappa = 0.79-0.93). Detail beyond that required to calculate pack-years thought to be hard to obtain. Observed that proxies tended to under-report the presence or level of exposure, meaning the specificity of proxy responses was better than the sensitivity for most exposures. Misclassification was found to be non-differential and accordingly, odds ratios computed using proxy data were similar in magnitude to those obtained using index data. The relationship of proxy to index was one reason for variation in reliability of response. Recommended order of priority for selection of proxies was spouse, sibling, child, parent, other relative and finally friend.
Novella, J.L. et al 2001 (25)	Cross sectional survey, Self-administered questionnaire carried out by index and two proxies	148	Assessment of quality of life using Duke Health Profile	Patients with mild to moderate Alzheimer's disease	Two proxies - (1) family member (2) care provider	Y	Y	Agreement between index and family proxy moderate for directly observable measures of function such as physical health (ICC=0.44) or disability (ICC=0.61), which was higher when examining only spouses as proxies (ICC=0.66 and 0.80 respectively). Agreement was worse for more subjective measures. Similar agreement observed when using health professionals as proxies: physical health ICC=0.69 disability ICC=0.53 when excluding nurses' aides. Proxies tended to underestimate quality of life as reported by index case. Agreement was especially weak for Duke subscales such as perceived health or social health.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Ostbye, T. et al 1997 (26)	Cross sectional survey. General survey of indexes, face to face interview of proxies	800	Assessment of activities of daily living	People aged 65 and older with or without dementia, part of a larger case control study of dementia and health	Caregivers	Y		Found proxies to be a reasonable source of data. Agreement decreases as severity of dementia increases. Agreement for PADL (kappa = 0.26-0.81 with the majority of values in the moderate category) is generally higher than for IADL (kappa = 0.18-0.61 with the majority of values in the fair category) Caregivers as proxies are not as reliable as other proxies, possibly because their judgement is impaired by their burden with respect to the index. The relationship of the caregiver to the subject did not appear to make an important difference to index-proxy agreement. Authors suggested that it is specific characteristics of the proxy such as amount of time spent with subject, or the 'quality' of the relationship, rather than their formal relationship to the subject, that affects quality of response
Passaro, K.T. et al 1997 (27)	Cross sectional study. Index and proxy both completed self-administered questionnaire	8414	Comparison of index reports of drinking and smoking habits	Husbands/partners of pregnant women participating in Avon Longitudinal Study of Pregnancy and Childhood	Pregnant women participating in Avon Longitudinal Study of Pregnancy and Childhood	Y		Very high percentage agreement by status, 95%. Good agreement by amount: agreement within one category = 90%, perfect agreement 81%. Percent agreement dropped dramatically when non-smokers were excluded (50%). Women tended to report lower amounts of smoking compared to men's self-reports when not in agreement. Almost perfect agreement for smoking status (98%, kappa = 0.74). Good agreement for amount: agreement within one category excellent (98%), and perfect agreement still good (71%). Women tended to report lower amounts of drinking compared to men's self-reports when not in agreement, overall agreement for drinking status substantial (kappa=0.74).

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Pierre, U. et al., 1998 (26)	Cross sectional survey. Self-completion of generic health questionnaire by index and 2 proxies in 2 settings: rehabilitation, and hospital.	86	Index-proxy agreement on perceived health status assessment	Inpatients in a rehabilitation setting or outpatients in a day hospital, aged 65 or older	1) friends and relatives who had had contact on at least 4 occasions in the past 2 weeks. 2) health care providers selected by indexes.		Y	Poor to moderate concordance agreement observed on all scales regardless of setting and type of proxy. Concordance was not found to be markedly better for observable physical activities than more subjective health status components. In rehabilitation setting: agreement with health professionals was moderate for mental health (ICC=0.41), bodily pain (0.42) and vitality (0.60). Agreement with family members was better: moderate for physical functioning (0.55), role physical (0.40), bodily pain (0.57), role emotional (0.44) and general health perception (0.58). Other questions elicited poor agreement. In the day hospital setting, agreement with health care professionals was moderate for physical functioning (ICC=0.45), general health (0.43) and mental health (0.41). Agreement with family proxy was substantial for physical functioning (ICC=0.71), moderate for vitality and mental health (ICC=0.40, 0.52 respectively). Agreement was poor for all other questions. Authors conclude that proxies were not able to provide information concordant with the index.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Poulter et al 1996 (29)	cross-sectional study. Face to face interviews of controls and their proxies.	403	Control-proxy agreement on current use of oral contraceptives in controls. agreement on a variety of exposures collected as part of the main study	Controls from case-control hospital-based study of current use of oral contraceptive s; women. women matched to cases (who were women aged 20-44, admitted to hospital with a first time diagnosis of three diseases) by hospital and age band	Relatives or friends of controls	Y	Y	The authors found that the optimal category of proxy to use is question specific, although husbands were usually the best proxy, based on kappa scores. Kappa ranged from: husband 0.39-0.90; mother 0.11-0.88; sister 0.14-91.7. Kappa and exact percentage agreement for husband was highest in all categories. Levels of concordance were high for most variables regarding recent events, and greatly diminished when detailed information, particularly from the past, was required. E.g. reporting of current contraceptive use: ICC=0.98 (husband) 0.52 (mother) as compared with reporting of past contraceptive use: ICC=0.79 (husband) 0.35 (mother).
Shalat, S.L. et al 1987 (30)	Cross-sectional survey of husband-wife pairs. Husband and wife were interviewed separately.	26	Husband's work history with respect to exposure to organic solvents	Male workers	Wife of index	Y	Y	Observed up to 88% concordance when pairs were directly asked a simple question regarding solvent exposure. Individual level husband-wife agreement was slight, kappa=0.18.

Study details	Study Design	n (pairs)	Outcome	Index	Proxy	Kappa	ICC	Comments
Shaw, C. et al 2000 <sup>(21)</sup>	Cross sectional survey. Face to face interview of index and their proxy within a few days	140	Assessment of functional ability	Women aged 65 years and older, part of a larger study of outcomes of fractured neck of femur post-surgery	Self-selected	Y		Proxy responses tend to be biased in the direction of overestimation of incapacity, with more proxies reporting that the index needed help for 3/4 of the questions asked. Concordance was 'substantial' for several categories, including cutting food ( $\kappa=0.68$ ), bathing ( $\kappa=0.75$ ), washing clothes ( $\kappa=0.72$ ) and cooking ( $\kappa=0.70$ ). The authors observed a tendency for improved agreement with more distant relationships and contact with the proxy. This is contrary to other findings, but may be because in the specific study population used, which was used to examine functional ability and continence in older people, the mood of the proxy who was frequently a caregiver, affected the quality of the proxy responses.
Tepper et al 1996 <sup>(22)</sup>	Cross-sectional survey. Interviews of indexes and proxies.	148	Agreement between index and proxy on a number of exposures related to recovery after traumatic brain injury	Traumatic brain injury patients	'Significant to others'	Y		Observed increased index-proxy agreement when the issues being addressed were readily observable: agreement substantial or ulcers ( $\kappa=0.91$ ), cancer( $0.89$ ), diabetes( $0.84$ ) and lung disease( $0.77$ ), for pairs within which neither respondent answered 'don't know'. Moderate agreement ( $\kappa<0.6$ ) observed for less easily observable medical conditions heart disease, stroke, liver disease and high blood pressure.



## **Chapter 2 The Russian mortality crisis**

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This thesis is concerned with an exploration of issues associated with the use of proxy respondents, using data collected by a case-control study of premature male mortality in Russia. In order to provide the context for this study, this chapter provides an overview of the Russian mortality crisis.

### **2.1 Summary of chapter contents**

This chapter begins by describing the low and dramatically fluctuating life expectancy in Russia over the past few decades. It then outlines the evidence to date which implicates alcohol as a possible causal factor driving these fluctuations, and introduces the Izhevsk Family Study, conceived to address the association between recent alcohol consumption and mortality.

### **2.2 Poor life expectancy in Russia**

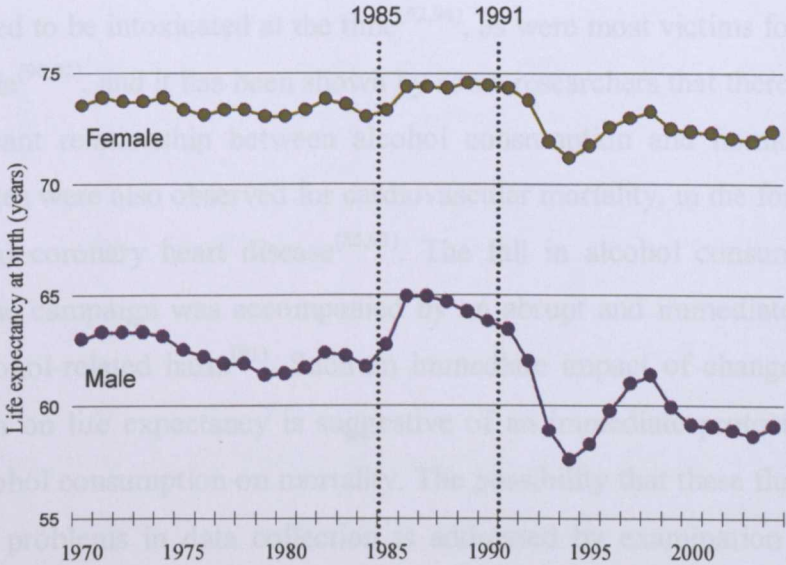
Life expectancy in Russia has been falling since 1965<sup>(73)</sup>. The shrinking population is expected to continue to decline by over 30% during the next half century, a decline unprecedented among industrialised countries<sup>(74)</sup>. As in other former Soviet states, life expectancy in Russia among men in particular has been consistently low over the past 50 years, but whilst in many other countries in the Commonwealth of Independent States<sup>a</sup> life expectancy has started to improve, Russia's life expectancy remains low, following gradually falling mortality rates between 1965-1980 and dramatic fluctuations in rates since 1985<sup>(75-78)</sup> (Figure 2.1). These fluctuations included an unprecedented, dramatic drop in life expectancy following the collapse of communism in 1991<sup>(79)</sup>. The gender gap in life expectancy has widened during recent years: by 1993, male and female life expectancy had fallen to 59.0 and 70.0 years respectively, and according to the most recent data compiled by the World

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<sup>a</sup> Commonwealth of Independent States, created in December 1991. Azerbaijan, Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Turkmenistan, Uzbekistan and Ukraine.

Health Organisation (2006), the average life expectancy for Russian men is 59.1 years, while that for Russian women is 72.4 years<sup>(80-82)</sup>, lagging behind EU member states by about 16 years for men and 9 years for women. The gender gap continues to increase<sup>(80,81)</sup>.

Figure 2.1 Russian life-expectancy at birth 1970-2002<sup>(81,83,84)</sup>



### 2.3 The role of alcohol

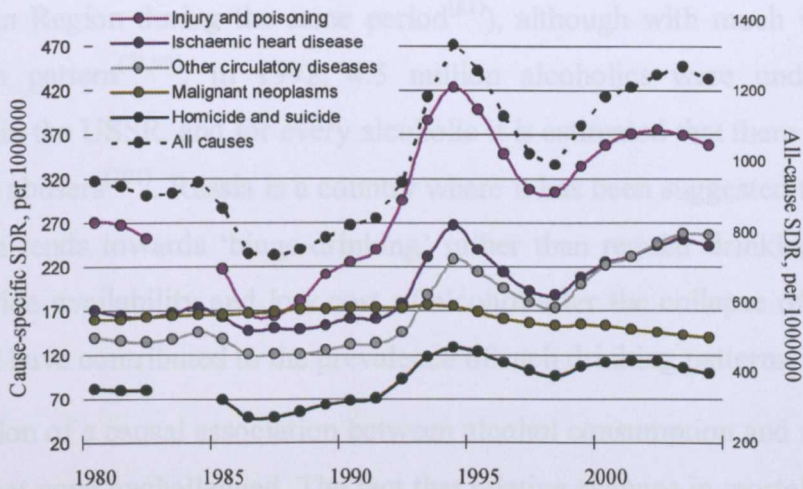
It has been widely suggested in the literature that alcohol is a major determinant of these recent mortality fluctuations<sup>(77,85-89)</sup>. An estimated 67 000 Russians die of alcohol poisoning each year, with a rural death rate for alcohol poisoning of 128 per 100 000 among adult men. Using a variety of indirect methods of estimation, it has been suggested that a third of total deaths in Russia are attributable to alcohol-related causes<sup>(89)</sup>. Following Gorbachev's anti-alcohol campaign of 1985-6, official alcohol consumption statistics indicated a radical fall in alcohol consumption<sup>(90,91)</sup>, and this was accompanied by an immediate rise in life expectancy among males. In the late 1980s the impetus of the anti-alcohol campaign reduced, and this was associated with an increase in alcohol consumption. After the collapse of the USSR in 1991 life

expectancy at birth sharply fell, providing indirect evidence of the role of alcohol in these mortality fluctuations.

Closer inspection of cause-specific mortality rates reveals that during this period of dramatic variation in all-cause mortality rates, the largest fluctuations were observed in alcohol-related causes, including acute alcohol poisoning and violent and accidental deaths<sup>(82,91-93)</sup> which unequivocally mirrored the pattern of all-cause mortality fluctuations. More than three quarters of all those convicted of homicide were reported to be intoxicated at the time<sup>(92,94)</sup>, as were most victims for whom data was available<sup>(90,92)</sup>, and it has been shown by some researchers that there is a positive and significant relationship between alcohol consumption and homicide rates<sup>(94)</sup>. Large changes were also observed for cardiovascular mortality, in the form of sudden death due to coronary heart disease<sup>(85,93)</sup>. The fall in alcohol consumption levels following the campaign was accompanied by an abrupt and immediate decrease in rates of alcohol-related harm<sup>(91)</sup>. Such an immediate impact of changes in alcohol consumption on life expectancy is suggestive of an immediate protective effect of reduced alcohol consumption on mortality. The possibility that these fluctuations are artefacts of problems in data collection is addressed by examination of mortality rates from cancers<sup>(77)</sup>, which would be expected to show a similar pattern of fluctuations to other causes if this were the case. However, as observed in Figure 2.2, these showed very little variation throughout this period.

However, the actual level of alcohol consumption in Russia remains unclear. It is difficult to obtain accurate estimates, since statistics on alcohol consumption only cover officially recorded sales and production, and unregistered sales and production are likely<sup>(85,88,90,91,95)</sup>. Attempts have been made to extrapolate sales by examination of gaps in official statistics<sup>(95)</sup>, and to estimate the amount of samogon – the predominant form of alcohol illegally produced – from the amount of surplus sugar sold in 1983-86, its key ingredient<sup>(91)</sup>, but nonetheless, it has been suggested that in recent years, the bulk of consumed alcohol has evaded official estimates<sup>(89)</sup>.

Figure 2.2 Cause-specific standardised death rate in Russian males aged 0-64, 1980-2004<sup>(81)</sup>



Correspondingly, some researchers have found alcohol consumption to be lower than expected. One study found alcohol consumption to be similar to that found in Finland and the proportion of adult men who drink daily to be lower than that in most of Europe<sup>(90)</sup>, and another survey found low levels of self-reported alcohol consumption in Russia<sup>(96)</sup>. It has been suggested by some researchers that there is a stigma attached to alcoholism<sup>(97)</sup> in Russia, which may be responsible for underreporting by what may be a greater extent than elsewhere, although others argue that drinking does not seem to bear a social stigma in Russian men, and therefore alcohol consumption is unlikely to be systematically underreported<sup>(98)</sup>.

Regardless, the reputation of Russia when it comes to alcohol is that of a nation of heavy drinkers with vodka occupying a central place in Russian life<sup>(88,90,95)</sup>. In his State of the Nation address on the 25<sup>th</sup> April 2005, President Vladimir Putin suggested that attention should perhaps turn to a subject ‘which is difficult for [Russian] society – the consequences of alcoholism’<sup>(99)</sup>. In Gorbachev’s opinion, vodka, which recently had its 500 year anniversary, ‘has done more harm than good to the Russian people’<sup>(100)</sup>. It is widely thought that the yearly consumption of alcohol is higher in Russia than anywhere else in the world<sup>(94)</sup>, and at least half of it<sup>(100)</sup>, even up to 75%<sup>(74)</sup>, in the form of vodka. It has been agreed by several authors



that alcohol consumption increased in the 1990s in Russia<sup>(88,90,94)</sup>, and in 1997, most estimates suggested that the level of alcohol consumption in Russia was 13-15 litres of pure alcohol per capita and rising (compared with between 8-9 litres per capita in the European Region during the same period<sup>(81)</sup>), although with much variation in consumption pattern<sup>(74,90)</sup>. In 1992, 4.5 million alcoholics were under medical observation in the USSR, and for every alcoholic it is estimated that there are three to four alcohol abusers<sup>(101)</sup>. Russia is a country where it has been suggested that alcohol consumption tends towards 'binge-drinking' rather than regular drinking<sup>(96,98)</sup>. The suspected wide availability and low cost of alcohol after the collapse of the Soviet Union could have contributed to the prevalence of such drinking patterns.

The suggestion of a causal association between alcohol consumption and mortality in Russia has not gone unchallenged. The fact that relative changes in mortality for men and women have been similar, despite currently very low levels of alcohol consumption in Russian women<sup>(90,96)</sup> has been taken to contradict the view that alcohol plays a major role in the mortality fluctuations<sup>(85)</sup>. In addition, Deev and colleagues found no clear association between alcohol intake and mortality after adjustment for other risk factors in the results of a cohort set up in Russia in the 1970s<sup>(102)</sup>.

In particular, attention has been paid by some researchers to the observed increases in deaths in Russia due to cardiovascular disease. This contradicts what has been established in Western populations about the association between cardiovascular disease and alcohol consumption. There is a well-established protective effect of moderate alcohol consumption on mortality from coronary heart disease<sup>(96,98,103-105)</sup>. However, it is thought that binge drinking is detrimental to health, contributing to a marked increase in cardiovascular morbidity and mortality, particularly mortality attributable to cardiovascular causes, including sudden cardiac death<sup>(93,106)</sup>. Such associations may be particularly important in Russia, although there is a lack of convincing supporting evidence to date. Britton and McKee<sup>(107)</sup> reported cardiovascular mortality to be increased in heavy or binge drinkers in a review of 7 studies investigating the association between heavy or binge drinking on cardiovascular disease. However, these studies could not differentiate between frequent heavy drinking and episodic binge drinking because of the indicators

used<sup>(98)</sup>. The Udmurt Study<sup>(108)</sup> found evidence of strong intoxication in at least 13.5% of deaths from cardiovascular disease, although not at levels usually thought to be fatal. The British Regional Heart Study<sup>(109)</sup> found heavy drinking to increase the risk of sudden cardiac death, but could not demonstrate overall increase in mortality from coronary heart disease in heavy drinkers. One study found the adjusted relative risk of cardiovascular mortality to be 2.05 (95% CI 1.09-3.86) in a small group of frequent heavy drinkers<sup>(98)</sup> although this was reported not to be necessarily associated with episodic binge drinking. Following the observation that deaths from cardiovascular disease increased at weekends, it was suspected that there was a link between binge drinking and cardiac death<sup>(93)</sup>. The health risks corresponding to binge drinking in Russia could have been further exacerbated by the lack of state control over the quality of obtainable alcohol.

It has been proposed that levels of alcohol consumption based on official estimates have been too low to produce such a large impact on mortality. It has also been suggested that an increase in alcohol consumption alone would not have been sufficient to explain the elevated mortality rates, and would have had to have been accompanied by a high increase in the relative risk related to alcohol, of a magnitude deemed unlikely: other factors such as socioeconomic deprivation, nutritional factors or psychosocial stress must therefore be responsible for the acuteness of mortality changes. Such factors, however, may of course be partly mediated by alcohol<sup>(85)</sup>. Traditional risk factors for cardiovascular disease such as smoking, physical activity and lipid levels have been found to have little predictive value in Russia and there is growing evidence that other factors are involved<sup>(93,110)</sup>. Additionally, it has been noted that the anti-alcohol campaign in Russia took place simultaneously with perestroika - other serious political and social changes – which could have had their own large impact on mortality<sup>(91)</sup>, although it is hard to imagine that such causes would have had such an immediate influence as that observed.

Whilst examination of the dramatic fluctuations in cause-specific mortality rates is suggestive of an acute exposure, the conclusion that alcohol is a causal factor is tentative due to poor knowledge of Russian alcohol consumption patterns, and the existence of contradictory views. At the end of the 20<sup>th</sup> century, there was a clear need for a well-defined study in this field<sup>(85)</sup>. The challenge to understand the reasons

behind such sharply fluctuating Russian mortality rates required detailed examination of exposures occurring shortly before death, and this approach was taken by the Izhevsk Family Study which began in 2003. This study addressed the hypothesis that the severe fluctuations in Russia, in particular in men of working age<sup>(74)</sup>, are attributable in large part to alcohol-related causes of death. The Izhevsk Family Study is described in detail in the following chapter.

## **Chapter 3 The Izhevsk Family Study: design overview**

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There is a consensus in the literature that further evidence is necessary to resolve uncertainties over the association between alcohol consumption and the historically observed acute fluctuations in mortality from many causes including cardiovascular deaths in Russia. The Izhevsk Family Study addressed this question with a case-control design that used proxy respondents, and focused on a central hypothesis: that the severe fluctuations in mortality in Russia, in particular in men of working age, are attributable in part to the effect of hazardous alcohol consumption. While the case-control study could not address this issue directly, it aimed to identify whether recent drinking was associated with mortality.

The methodological research presented in this thesis is based on data collected by the Izhevsk Family Study.

### **3.1 Summary of chapter contents**

This chapter begins by describing the Izhevsk Family Study aims, design and the rationale behind the use of a case-control study to address these study aims. It then describes the development of study methods including the protocol for selection of the best proxy respondent, and finally gives a detailed description of the sources of data collected, and development of the questionnaires.

### **3.2 Izhevsk Family Study aims**

The scientific aim of this project was to investigate which causes of mortality in working age men in Russia are associated with patterns of alcohol consumption. Specifically the study aimed to:

- a) Estimate the strength and direction of associations between recent and habitual alcohol consumption and risk of death (2002-2003) from specific causes among men aged 25-54 years in a major Russian city (Izhevsk)



- b) Identify socio-economic factors and other characteristics of individuals that are associated with mortality, especially those whose effects may be mediated through alcohol consumption

### **3.3 Background**

#### **3.3.1 Why a case-control study?**

Since the central exposure of interest was alcohol as a proximal exposure, the best study design for this research question was a case-control study, which allows detailed data collection on recent events and multiple exposures for a relatively rare outcome. Considering the aims of this study, a longitudinal study design could theoretically be appropriate, in which a cohort of men living in Russia could be interviewed at baseline and followed up until the occurrence of the stated outcome, death from any cause. Despite the advantage of being able to interview the indexes themselves, and reduce information bias due to case/control status of the index by prospectively, rather than retrospectively, collection data, a cohort design is not feasible in this Russian context for two reasons. Firstly, in order to be able to draw inferences about the link between mortality and recent drinking, it would be necessary to re-interview men at frequent intervals to ensure that detailed information on recent alcohol consumption was collected a short interval before death. This would be logistically complicated and extremely expensive and time-consuming. Secondly, the size of the cohort required would be prohibitively large: the case-control design succeeded in obtaining interviews for approximately 60% of deaths occurring in the entire male population of Izhevsk aged 25-54, according to official records. In order to obtain the same number of events in a cohort design, then assuming a similar response rate, it would be necessary to follow up the entire male population of Izhevsk aged 25-54 for a period of 3 years, or alternatively half this group for a period of 6 years (approximately 100 000 men), etc. In Russia at the present time, such a cohort would be very difficult to set up.

### 3.3.2 Study setting

The Udmurt Republic, population 1.6 million, is part of the Russian Federation. It is relatively highly urbanised: in 1998, 70% of its population was living in cities. The capital city, Izhevsk (population 700 000), is located 1300 km south east of Moscow in the middle Urals. The mortality profile of the Udmurt Republic is similar in most respects to that of Russia as a whole: in 2001, life expectancy at birth in the population of Udmurtia was just slightly higher (male: 58.8, female: 72.4) than the national figure (male: 59.0, female: 72.3)<sup>(111)</sup>, with similar patterns of mortality by age and cause of death, with the exception of suicide, which in the Udmurt Republic is appreciably higher than the Russian average.

Table 3.1 shows the mortality distribution of 3274 men aged 25-54 identified by the Izhevsk Family Study in 2003, and the distributions for Udmurtia and Russia as a whole for the same period. It is clear that the mortality distribution in Izhevsk is broadly representative of that in each of the two larger regions.

*Table 3.1 Comparison of death distribution in Izhevsk with Udmurtia, and Russia as a whole, in males aged 25-54 in 2003<sup>(84)</sup>*

Cause of death	Russia 2003		Udmurtia 2003		Izhevsk study	
	n	%	n	%	n	%
Infectious and parasitic diseases	21608	4.9	227	4.2	98	3.0
Cancer	33111	7.5	341	6.3	195	6.0
Mental and behavioural disorders	3733	0.8	80	1.5	33	1.0
Circulatory disease	133580	30.2	1448	26.6	914	27.9
Respiratory disease	25107	5.7	404	7.4	293	8.9
Digestive disease	25914	5.9	455	8.4	313	9.6
External causes	165884	37.6	2264	41.6	1226	37.4
Other causes	32704	7.4	221	4.1	202	6.2
Total	441641	100	5440	100	3274	100

### 3.4 Summary of design

The Izhevsk Family Study is a case-control study based on 1750 deaths from all causes among male residents aged 25-54 years of the city of Izhevsk, registered over a twenty-four month period (2003-5). Notification of cases was received from the

city vital registration bureau (ZAGS), and male controls were selected at random from computerised voters lists (which include name, address, date of birth and sex), and were frequency-matched to cases by age group on aggregate. Interviews were conducted with proxy informants who live(d) in the same household as the case or control by trained interviewers using questionnaires to elicit information on alcohol consumption and associated behaviours, socio-economic circumstances, employment, education, smoking and other behavioural factors. Controls themselves were also interviewed. Apart from the questionnaire, four external sources of information were also employed: direct evidence of alcohol abuse was obtained from records of treatment in the city Narcology Dispensary (Izhevsk's alcohol and drug treatment clinic); objective information about cause of death was collected at autopsy, which was carried out for all cases; evidence of any prison stays was obtained from police records; evidence of current benefits obtained and disability status were collected from the Social Security bureau.

#### **3.4.1 Piloting phase**

The questionnaire and other data collection methods were piloted during the period May – July 2003. This was an iterative process with 5 distinct stages, described in Table 3.2 below. All piloting was carried out in Izhevsk.

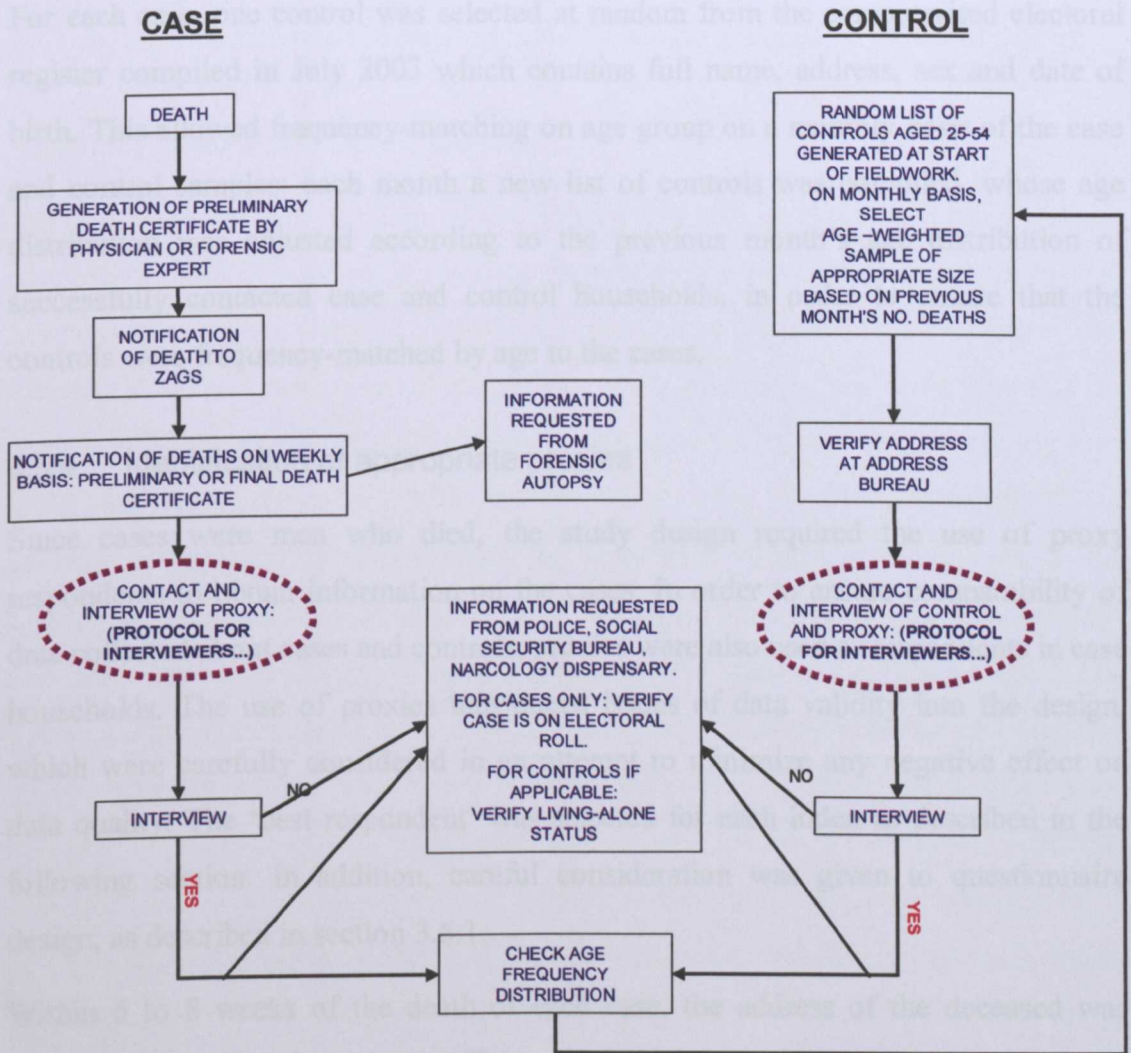
**Table 3.2 Pilot stages carried out May-July 2003**

Stage	Description	n	Instruments being piloted	Purpose of stage	Comments
1	Small scale pilot on friends and colleagues	10	Questionnaire Respondent selection protocol	Acceptability, unambiguity, Length Success in selecting appropriate subjects	
2	Larger pilot of persons selected at random	20	Questionnaire and respondent selection protocol, Subject information sheet, Process form, Consent form	All of above & Obtain consent successfully Clarity and usefulness of process forms	Carried out after amendments to questionnaire and screening form from stage 1.
3	Pilot of cases	20	Questionnaire and respondent selection protocol, Subject information sheet Process form, Consent form, Electoral role	All of above & System for tracing cases	Carried out following further refinement of questionnaire and amendments to the three forms from stage 2.
4	Incremental piloting of smaller sub-systems	-	Forensic autopsy, Medical Death certificate, Civil death records, Narcology Dispensary, Police records of any prison stay, Social Security Bureau	All of above & Efficiency of systems for obtaining external data. Attempts were made to trace information on all subjects interviewed since start of pilot.	Continuous refinement of methods used to extract data from the sources listed.
5	Full 'dress rehearsal'	189 control households, 128 case households	Questionnaire and respondent selection protocol, Subject information sheet, Process form, Consent form, Electoral role, Forensic autopsy, Medical Death certificate, Civil death records, Police records of any prison stay, Narcology Dispensary. Social protection Bureau	All of above & Efficiency of systems for obtaining external information on subjects	Carried out following further amendments to all instruments following all previous stages.

### 3.5 Description of methods

The flow of information in the Izhevsk Family Study is illustrated by Figure 3.1

Figure 3.1 Detailed information flow



#### 3.5.2 Case definition

Cases were male Izhevsk residents aged 25-54 years dying from any cause. All deaths in the city were notified to the study team within 10 days of occurrence through links with medical institutions, and the local statistical bureau (ZAGS). Copies of the medical and civil death certificates were obtained with cause of death

coded to the 10<sup>th</sup> revision of the International Classification of Diseases (ICD). All relevant routinely collected information from autopsy reports (including blood alcohol in the case of forensic autopsies) was also collected. This enabled assessment of the validity of the certified cause of death.

### 3.5.3 Control definition

For each case, one control was selected at random from the computerised electoral register compiled in July 2003 which contains full name, address, sex and date of birth. This allowed frequency-matching on age group on a monthly basis of the case and control samples: each month a new list of controls was compiled, whose age distribution was adjusted according to the previous month's age distribution of successfully contacted case and control households, in order to ensure that the controls were frequency-matched by age to the cases.

### 3.5.4 Identification of appropriate proxies

Since cases were men who died, the study design required the use of proxy respondents to obtain information on the cases. In order to ensure comparability of data collected about cases and controls, proxies were also used as respondents in case households. The use of proxies introduced issues of data validity into the design, which were carefully considered in an attempt to minimize any negative effect on data quality. The 'best respondent' was selected for each index as described in the following section. In addition, careful consideration was given to questionnaire design, as described in section 3.6.1.

Within 6 to 8 weeks of the death of each case, the address of the deceased was visited by a trained interviewer. This period was selected in order to respect the traditional 40 day mourning period, whilst simultaneously minimising recall time. The interviewer established whether the case lived at that address at the time of death, and whether there was a suitable informant with knowledge of the study subject living in the household who would be prepared to be interviewed. Records were kept of all attempted visits to households regardless of outcome. The detailed protocols pertaining to the procedure of proxy selection and courses of action when

the listed address was not correct is included in *Appendix 1*, along with documents developed to record this aspect of the fieldwork.

For controls, interviews were carried out within 4 weeks of the date of issue of the subject to the fieldwork team, in order to maximise comparability with the case protocol. The address of interest was that at which the control currently resided.

Controls and their proxies were interviewed at approximately the same rate as case proxies, with frequencies matched on age distribution adjusted on a monthly basis.

### *Selection of the best proxy informant*

In accordance with the findings of the literature review in Chapter 1, one approach adopted to maximise the validity of the responses was to select the proxy who was most likely to have directly observed - and hence be able to remember - the characteristics and behaviour of the index over a mid-term time scale (the past 12 months or longer before death/the current time) as well as over a very short-term time scale (the week before death/the current time). This permitted investigation of behaviours immediately before death that may have caused or contributed to the death. The 'best informant' was someone who had been living with the index for an unbroken period of at least 6 months at the current time/at the time of death (for cases). Where there was more than one potential informant with comparable duration of co-residence the individual was selected according to their relationship to the index, in the order prescribed by the literature review findings: wife/girlfriend/partner, sister, mother, brother, father, offspring, other. A number of possible situations made selection of the best respondent less straightforward; during piloting stages a detailed protocol was developed in order to guide the proxy selection in all circumstances. For example, where the index lived alone they were simply excluded. If, however, the index had recently moved out of his permanent residence to a new address *without* the rest of his household or the potential informants had recently moved away from, or in to, the index's permanent residence and had therefore not lived with the index continuously for the previous 6 months, interviewers followed a series of detailed steps to ensure a consistent proxy selection process. This protocol is found in *Appendix 1*, and was used by the interviewer in every household visited, at the point of initial contact.

### 3.5.5 Interviews

Each month, a list of cases and a list of controls were supplied to the fieldwork team (the case list being compiled from information obtained from ZAGS, and the control list being compiled to match the age distribution of cases, from the list of possible controls obtained from the electoral roll). The households were allocated to the interviewers, who then attempted to locate the addresses supplied within the prescribed time period. The outcome of every household visit was recorded on case/control 'navigation sheets' (Appendix 1). Once a household was located, and the best available proxy respondent identified, the interviewer gave the respondent an information sheet describing the study aims and methods and assuring the respondents of confidentiality of information (Appendix 1). Verbal consent was then obtained by the interviewer before carrying out the interview. This was obtained in preference to written consent due to awareness of local cultural issues regarding fear of signing official documents, and concerns regarding how this would impact respondent participation.

A protocol described the procedure to be followed by interviewers when attempting to obtain case or control interviews. In control households, there was a particular concern regarding data contamination between control and control proxy interviews which could lead to data quality problems. In order to avoid data contamination, interviewers were required to obtain the control interview either on the same visit to the household as that during which the proxy was interviewed, or on a subsequent one. Proxies were encouraged not to discuss the content of the interview with the control, also in order to avoid contamination of the control responses by the proxy. In both case and control households, it was recommended that nobody was in the room during the whole, or part of, the interview, since this could influence responses. Any interruptions or lack of privacy were recorded by the interviewer. The questionnaire is discussed in detail in section 3.6.1. The entire fieldwork process was summarised in an information pack compiled by the fieldwork coordinator and supplied to interviewers, 'Description of questionnaire survey fieldwork', found in Appendix 2.



### *Validation interviews*

In addition to the interviews with case proxies, control proxies and controls, in a subset of households, a second proxy of a different informant type were also interviewed (e.g. wife *and* mother). This was restricted to 200 case and 200 control households. This number was chosen to be feasible given limited resources. Validation interviews were carried out specifically to allow an assessment of the extent to which the relationship of the informant to the index influences response, since they provided a sample of households in which different proxy types can be compared, whilst automatically controlling for known and unknown attributes of the index which may affect the validity of proxy responses.

During the period November 2004 – July 2005 when validation interviews were being undertaken, interviewers were instructed to complete the 1<sup>st</sup> proxy interview as normal, and for control households also the control interview, in accordance with the usual protocol. It was only at the end of the core interview(s) that the interviewer enquired whether there was a second respondent willing to be an informant. This order of events protected the usual interviews from being affected by the additional validation interviews.

If an additional proxy respondent agreed to being interviewed, the interviewer was instructed to carry out this validation interview immediately if possible in order to minimise data contamination. If more than one additional proxy informant was available, it was deemed preferable to obtain any additional interview straight away than to return later: i.e. to prioritise timing of the validation interview over respondent choice. If it was not possible to obtain a potential validation interview immediately, the interviewer returned at a later time convenient to both parties, at the earliest opportunity. Validation interviews were attempted in all households until the target number was reached.

## **3.6 Sources of information**

### **3.6.1 Questionnaire**

Collection of high quality data is dependent on the study tools, which in this context is the questionnaire used to collect data from the index and proxy. A questionnaire can be assessed in two ways: validity and reliability. A reliable questionnaire collects information that is replicable<sup>(112)</sup>, whilst a valid questionnaire is one that collects the information it was intended to collect<sup>(112)</sup>. Both reliability and validity were deemed essential qualities of the questionnaire designed for use in the Izhevsk Family Study.

Initial development of the questionnaire in English took place over a number of months. Once the broad content was agreed by the study team, examples of questions were adapted from questionnaires used in similar studies<sup>(113-116)</sup>. Consistent with findings of the literature review in Chapter 1, questions asked of proxies about the behaviour and characteristics of index subjects were as far as possible restricted to directly observable and factual issues to minimise bias. Questions on self-reported health were, by definition, inappropriate and therefore excluded. Questions from other studies were modified according to the style necessary for this study and drawing on local and sociological expertise: many of the questions developed elsewhere have not been for this type of study and not intended for proxy respondents, so modifications were considerable. Once the content was agreed in detail in English, the three questionnaires (case proxy, control proxy, control) were translated into Russian, then back-translated to check the fidelity and accuracy of translation.

Modifications to the questions used and the way in which they were phrased were made following each of the multiple piloting stages, as outlined in Table 3.2, and were influenced by the conclusions of the literature review investigating validity of proxy responses (Chapter 1), by findings of analyses carried out to investigate the agreement between control and control proxy responses to the same questions using Cohen's kappa coefficient on data collected during early piloting phases (Appendix 4), and by feedback obtained following each piloting stage. The questionnaire went through 8 iterations before reaching the final version which was agreed by the start of the fieldwork on the 18<sup>th</sup> December 2003, with the exception of a few minor

updates made in January 2004. The final English version of the case-proxy questionnaire is reproduced in Appendix 3.

The questionnaire was interviewer-administered and elicited information on recent and longer term alcohol drinking habits, socio-economic circumstances, employment, education, smoking and other behavioural factors. Reported use of health services in the previous year and doctor-diagnosed illness were also recorded. The three questionnaires were identical apart from the appropriate rephrasing that allowed them to be administered to three different types of respondent (case proxies, control proxies, controls), an additional section in proxy questionnaires collected information on the proxies themselves, and an additional section in the case proxy questionnaire about circumstances surrounding the death of the case. A summary of modules within the questionnaire is presented in Table 3.3.

**Table 3.3** *Summary of questionnaire module content*

<b>Section</b>	<b>Number of questions</b>	<b>Summary</b>	<b>Case proxy</b>	<b>Control proxy</b>	<b>Control</b>
A	20	Proxy socio-demographic details, including education and occupation	✓	✓	
B	7	Area and crime information	✓	✓	✓
C	18	Household composition and assets	✓	✓	✓
D	6	Vital status of subject's parents	✓	✓	✓
E	15	Index-proxy relationship, and socio-demographic details on subject	✓	✓	✓
F	17	Education and occupation of subject	✓	✓	✓
G	11	Subject's recent life events and social networks	✓	✓	✓
H	10	Circumstances surrounding the death (case proxies only)	✓		
J	10	Diseases and disabilities of the subject	✓	✓	✓
K	11	Health and health related behaviour during past year of subject	✓	✓	✓
L	39	Alcohol use - quantity, frequency, pattern and indicators	✓	✓	✓
M	6	Tobacco use	✓	✓	✓
X	7	Interviewers comments - reliability, difficulty, interruptions	✓	✓	✓

### **3.6.2 External sources of data**

Three external sources of data were collected in addition to questionnaire responses for all subjects, independently of interview outcome. All three sources of data are administrative sources of data, so benefit from not being prone to the same subjective biases as questionnaire responses, and were collected independently of the Izhevsk Family Study, and prior to the death of cases. Since information was recorded prior to the death of the case, it was effectively ascertained blind to case-control status. The three external data sources examined, Narcology Dispensary registration, Social Security registration, and Police records of a prison stay, are described in detail in Chapter 4, section 4.5.2.

### **3.7 Ethical approval**

Ethical approval for this study was obtained from the London School of Hygiene and Tropical Medicine ethics committee, as well as from the Izhevsk Medical Academy Ethics Committee.

### **3.8 A unique opportunity**

As described in Chapter 1, much work on the quality of proxy responses has been done as off-shoots of other studies. For example, studies examining elderly patients or patients with impaired mental health have sometimes used carers or next of kin as informants, and as a result have had a dataset which can be used to examine the reliability and validity of proxy respondents. However, the findings of such studies are not widely generalisable since they are based on a very particular subset of people.

The opportunity provided by the Izhevsk Family Study is a unique one: as described in detail in this chapter, for each healthy control interviewed, an interview is also carried out on a proxy respondent. These data can be used to examine the quality of data obtained from proxy respondents in an unselected population by comparison with index data. Moreover, in a subset of control and case households, an additional proxy interview was undertaken, thereby providing data that allows evaluation of different types of proxies whilst holding the index and corresponding confounding

factors constant. Independent, objective data on alcohol exposure, police records and Social Security were also collected, against which proxy and index responses can be compared. The following chapters describe the data and methods used to investigate the validity and reliability of data, and the impact on study findings, of using proxy respondents in a case-control study.

## **Chapter 4 The Izhevsk Family Study: data collection and processing**

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As described in Chapter 3, the Izhevsk Family Study provides a unique opportunity to explore the validity and reliability of responses provided by proxy respondents, and the impact their use has on study findings, both within the context of a case-control study where cases have died, and also, unusually, among a population sample of healthy controls. This chapter describes the data in terms of response rate and respondent/subject key characteristics, and outlines the cleaning and restriction processes applied to the Izhevsk Family Study data in order to prepare it for the analyses which are presented in the following chapters. It also introduces a summary of the variables selected for the analyses in this thesis.

### **4.1 Summary of chapter contents**

This chapter provides a description of the data cleaning process carried out on the Izhevsk Family Study data. It then describes the study respondents in terms of response rate, proxy types and key proxy and index subject attributes. Finally, this chapter provides a description of the key variables used in the analyses, including informative variables regarding interview quality used to restrict the data to eligible subjects, descriptive variables regarding the index-proxy relationship used to restrict the data to subsets, and the specific exposures investigated.

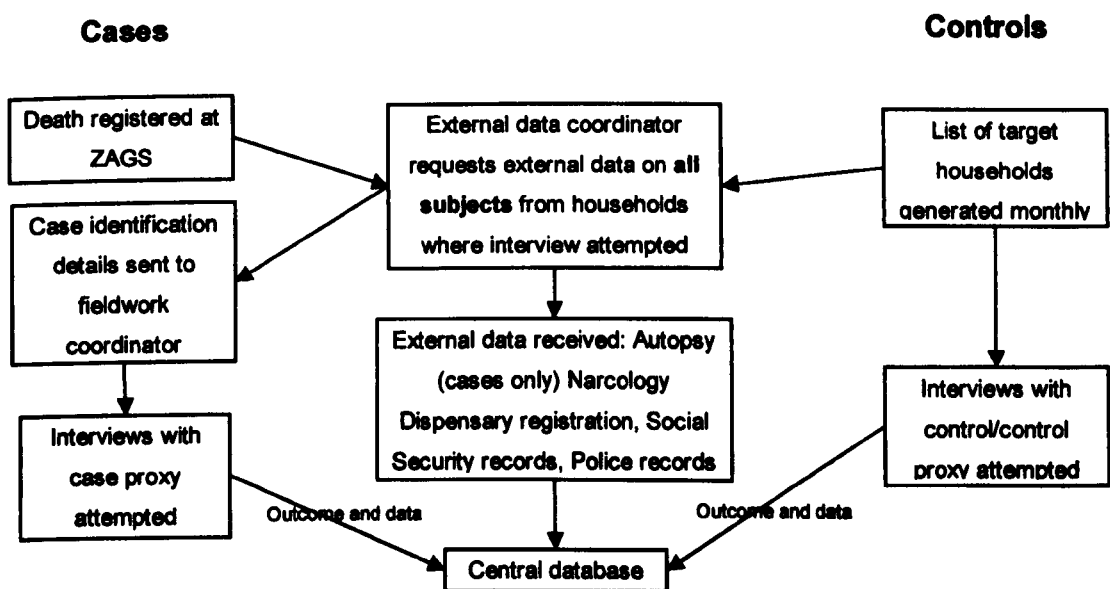
### **4.2 Data entry and cleaning**

Questionnaire variables were initially entered into an SPSS database in Izhevsk, using double entry, range and consistency checking in order to minimise data entry errors. Data were then transferred to a STATA format using StatTransfer software. All external data were initially entered into Excel spreadsheets by collaborators within the relevant external organisations. The data were sent to the study team and were transferred to a STATA format using StatTransfer software. After transfer, data were checked for outliers, implausible values and possible errors and corrected as appropriate, referring back to original documents if necessary. Labelling of all data

was carried out in English. Data was then checked for anomalies and outliers which were corrected where possible by referring back to original documents, including accidental entry of Russian characters rather than Latin characters into database. Cross-checking between different data sources was carried out for variables such as date of birth, to check for consistency and errors. Causes of death obtained from autopsy records were carefully checked in order to ensure consistency in cause of death category for underlying versus direct causes, and variables detailing the address of the index and interview timing were examined to ensure adherence to study inclusion criteria.

Several datasets were then merged based on a unique ID number: three sets of questionnaire data (case proxy, control proxy, control), lists of cases and controls, autopsy data, social security data, police data, narcology data and ZAGS data. After merging, the combined dataset was carefully cross checked to ensure the correct records had been successfully combined for every subject.

*Figure 4.1 Information flow: interviews and external data*



### **4.3 Description of respondents**

#### **4.3.1 Response rate**

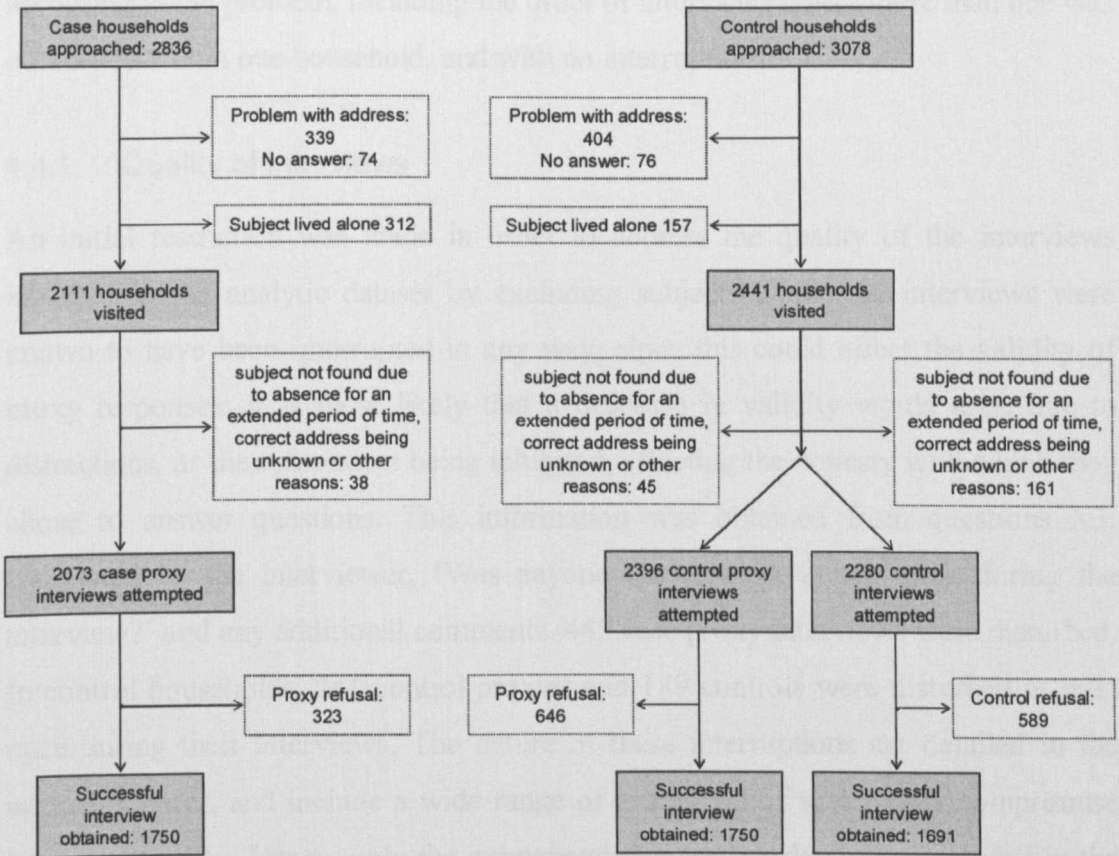
Between 18<sup>th</sup> December 2003 and 16<sup>th</sup> November 2005, 2836 case households were identified for interview attempts. There were problems identifying the correct address for 339 and for 74 there was no answer at the door. Of the remaining 2423 households, 312 (13%) cases had lived alone and were therefore excluded, and in a further 38 (14%) households, no respondent was found or there were other problems identifying proxies. 1750 successful case proxy interviews were obtained representing a response rate of 84%. Of these interviews, 59% of respondents were with the wife, girlfriend or spouse, and 19% were with the case's mother.

Within the same period, 3078 control households were identified for interview attempts. There were difficulties identifying the correct address for 404 and for 76 there was no answer at the door. Of the remaining 2598 households, 157 (6%) subjects lived alone and were therefore excluded, and in a further 45 households, no respondent was found, the subject had died or there were other problems identifying respondents. 1750 successful proxy interviews were obtained representing a response rate of 73%, and 1691 successful control interviews were obtained, representing a response rate of 74%. Of the proxy interviews, 85% of respondents were with the wife, girlfriend or spouse, and 9% were with the control's mother. Of the index interviews, 111 were in households where no proxy interview was obtained, resulting in 1580 households in which both a control and control proxy interview were conducted. These 1580 pairs of interviews were obtained from 2235 control households in which an index and proxy respondents were both available, representing a lower response rate of 71%.

It is of interest that the proxy refusal rate was much higher in control households than in case households (27% versus 16% respectively of households in which one or more eligible proxy respondents had been identified). This may be attributable in part to increased motivation among proxies of men who had recently died to contribute to research concerned with causes of death than among proxies of still-living controls.



Figure 4.2 Outcome of attempts to locate and interview case proxy, control proxy and control respondents



#### 4.4 Restriction: eligibility for analysis and descriptive subsets

A reduction in sample size, for whatever reason, has the result of decreasing the precision of obtained estimates<sup>(117,118)</sup>. There is therefore a trade-off between minimising bias in data by excluding certain subjects, and maintaining a sufficiently large sample size to be able to detect effects with precision. If the reduction in sample size is large, then the consequent reduction in precision may be substantial. By applying exclusion criteria in order to exercise greater control over the subjects included in a study, it is recognised that in addition to reducing ‘noise’ inherent in the data, the generalisability of study findings is itself directed away from a ‘real world’ setting in which interruptions to interviews, for example, are likely.

However, in this thesis, very specific issues are being addressed regarding the validity of responses given by proxies to questionnaires and it was therefore decided to restrict the analytic dataset to those individuals where the interview process went according to the protocol, including the order of interviews where more than one was conducted within one household, and with no interruptions.

#### 4.4.1 Quality of interviews

An initial restriction was made in order to address the quality of the interviews included in the analytic dataset by excluding subjects where the interviews were known to have been interrupted in any way, since this could affect the validity of proxy responses: it is most likely that a decrease in validity would arise due to distractions, or the respondent being inhibited, affecting the honesty with which they chose to answer questions. This information was obtained from questions X3, completed by the interviewer, ‘Was anyone else present at any time during the interview?’ and any additional comments. 445 case proxy interviews were disturbed. In control households, 241 control proxies and 189 controls were disturbed at least once during their interviews. The nature of these interruptions are detailed in the interview notes, and include a wide range of events, all of which may compromise interview quality. Hence, only the uninterrupted interview data were included in the analytic dataset.

**Table 4.1** *Was anyone else present at any time during the interview?*

Respondent type	Yes		No		Total	
	n	%	n	%	n	%
case proxy	445	25.4	1305	75.6	1750	100.0
control proxy	241	13.8	1509	86.2	1750	100.0
control	189	11.2	1502	88.8	1691	100.0

It was stipulated in the study protocol that the control proxy interview should be completed either first, or on the same visit as the control interview. This was in order to minimise contamination of proxy data by respondents having the opportunity to discuss the question content in the time between interviews. In around 90% of the 1509 control households in which an uninterrupted control proxy interview was

carried out, this was achieved, whilst in 122 households it was not. Information about this was consistent in both sets of interview notes for all control-proxy pairs. The control proxy interviews carried out in those 122 households were excluded from the analytic dataset.

*Table 4.2 Relative timing of interviews in control households*

Timing of interviews	n	%
Both on same day	1047	77.2
Not on same day: Control proxy first/only	340	13.8
Not on same day: Control proxy second	122	9.0
Total	1509	100.0

After the exclusions described above, the remaining dataset comprised 1305 case proxy interviews, 1387 control proxy interviews and 1140 control interviews in households in which a control proxy interview was also obtained.

#### 4.4.2 Proxy characteristics

The self-reported characteristics of proxies did not vary substantially between case and control households. Among both sets of 1750 proxies, the vast majority of respondents were female, and the age distribution roughly approximated a normal distribution, with most proxies aged 31-40, and very few aged less than 20 or years. The most striking observed difference was that the vast majority of control proxy respondents reported living together with their spouses, whilst the vast majority of case proxy respondents were widowed. Over 60% of both case and control proxies reported their ethnicity to be Russian, with the remainder tending to be either Udmurt or Tatar, and around 3% reporting themselves to be of other ethnicity. The proportion of respondents who were born in Izhevsk was only slightly less than half for both types of household, and almost all respondents had lived in Izhevsk for at least 10 years. A higher proportion of control proxies had achieved partial or complete higher education, and a slightly higher proportion of control proxies had specialised or professional secondary education; case proxies were more likely to only have partial or complete secondary education. The majority of proxies were in regular paid employment, and very few of either type of proxy reported being registered disabled.

The distribution of these self-reported socio-demographic characteristics is illustrated by Figure 4.3 (case proxies) and Figure 4.4 (control proxies) on page 73. It can be seen from these figures that the self-reported characteristics of those proxies remaining in the analytic dataset after carrying out the above exclusions show an extremely similar distribution to those in the unrestricted dataset in both types of household.

#### 4.4.3 Formal index-proxy relationship

The distribution of case and control proxies according to their formal relationship to the index is illustrated by Table 4.3. For both types of index, the vast majority of respondents are the wife, girlfriend or spouse of the index, although this proportion is clearly higher among controls than cases (86% versus 60%), who correspondingly have a higher proportion of mothers as respondents than controls (18% versus 8%). All other types of relationship are poorly represented, with only a few respondents of each type for both controls and cases.

*Table 4.3 Index-proxy relationship as reported by proxy*

Relationship to index	case proxy		control proxy	
	n	%	n	%
wife/girlfriend/partner	785	60.2	1,191	85.9
mother	238	18.2	115	8.3
father	19	1.5	7	0.5
brother	31	2.4	7	0.5
sister	56	4.3	11	0.8
daughter	57	4.4	16	1.2
daughter in law	1	0.1	1	0.1
son	46	3.5	25	1.8
son in law	2	0.2	0	0.0
other relatives	32	2.5	5	0.4
other	38	2.9	9	0.7
<b>Total</b>	<b>1,305</b>	<b>100.0</b>	<b>1,387</b>	<b>100.0</b>

Figure 4.3 Percentage self-reported case proxy characteristics before and after exclusions

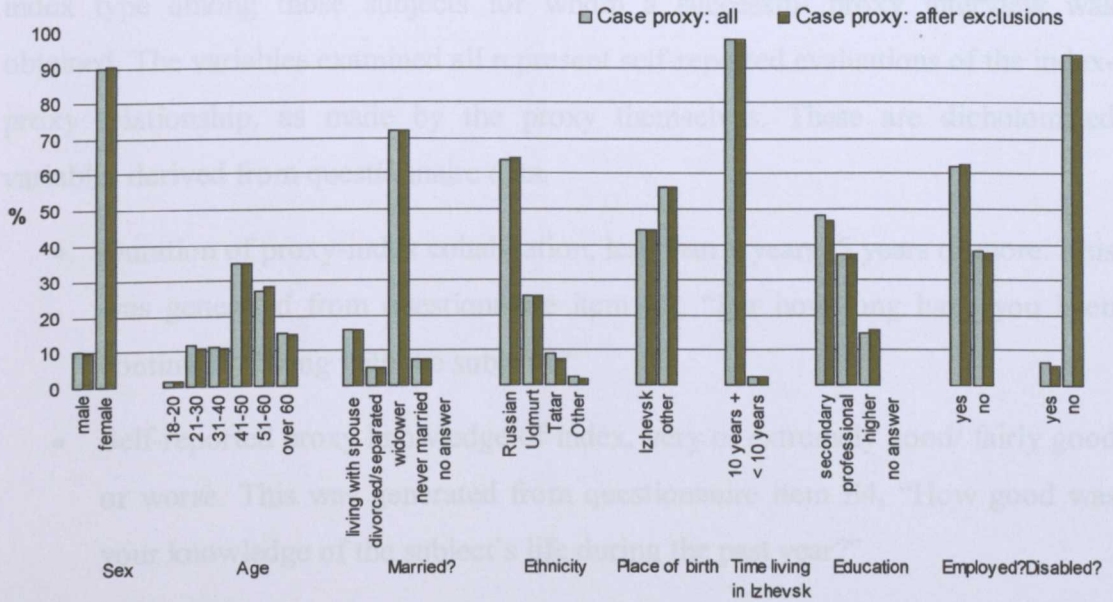
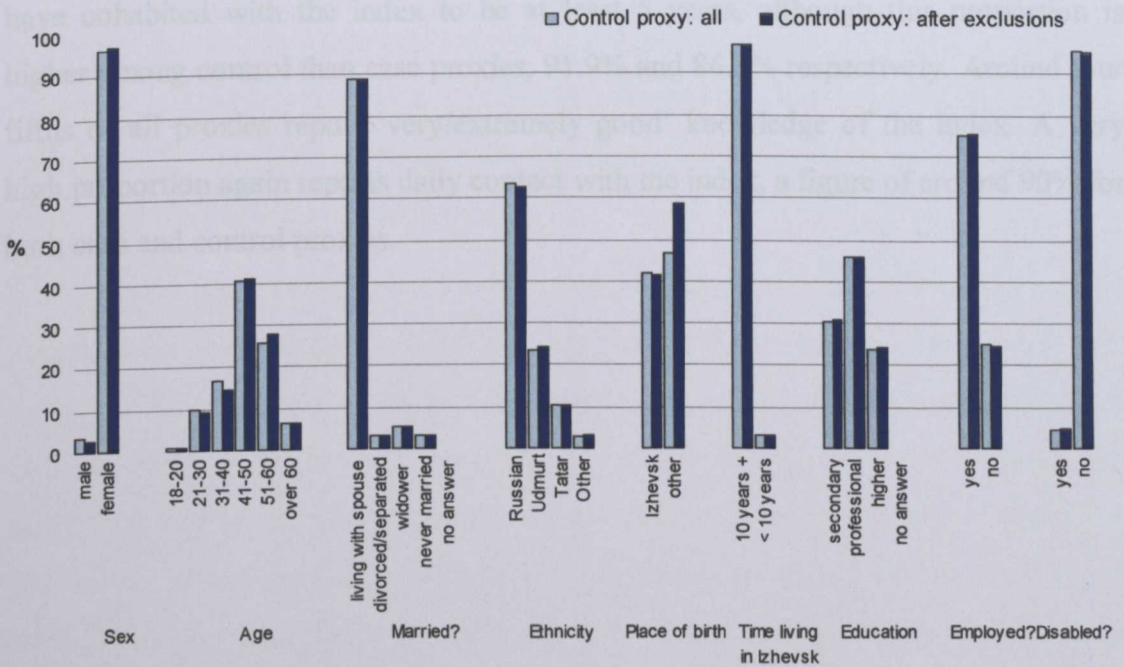


Figure 4.4 Percentage self-reported control proxy characteristics before and after exclusions



#### 4.4.4 Proxy-reported characteristics of the index-proxy relationship

The distribution of proxies by the explanatory variables describing the strength of the index-proxy relationship was obtained using cross tabulations of these variables by index type among those subjects for whom a successful proxy interview was obtained. The variables examined all represent self-reported evaluations of the index-proxy relationship, as made by the proxy themselves. These are dichotomised variables derived from questionnaire data.

- Duration of proxy-index cohabitation, less than 5 years/ 5 years or more. This was generated from questionnaire item E2, “For how long have you been continually living with the subject?”
- Self-reported proxy knowledge of index, very or extremely good/ fairly good or worse. This was generated from questionnaire item E4, “How good was your knowledge of the subject’s life during the past year?”
- Frequency of index-proxy contact, every day/ several times per week or less. This was generated from questionnaire item E5, “How often did you usually see the subject during the past year?”

The distribution of attributes pertaining to the index-proxy relationship is shown in Table 4.4. The vast majority of all proxy respondents report the amount of time they have cohabited with the index to be at least 5 years, although this proportion is higher among control than case proxies, 91.9% and 86.3% respectively. Around four fifths of all proxies report ‘very/extremely good’ knowledge of the index. A very high proportion again reports daily contact with the index, a figure of around 90% for both case and control proxies.

**Table 4.4** *Characteristics of the index-proxy relationship among case and control proxies*

Question		Case proxies		Control proxies	
		n	%	n	%
Duration of proxy-index cohabitation	< 5 years	177	13.6	112	8.1
	5 years +	1,126	86.3	1,275	91.9
	missing	2	0.2	0	0.0
	Total	1,305	100.0	1,387	100.0
Proxy knowledge of index	very/extremely good	1,034	79.2	1,170	84.4
	fairly good or worse	270	20.7	211	15.2
	missing	1	0.1	6	0.4
	Total	1,305	100.0	1,387	100.0
Frequency of proxy-index contact	several times per week	125	9.6	115	8.3
	every day	1,169	89.6	1,258	90.7
	missing	11	0.8	14	1.0
	Total	1,305	100.0	1,387	100.0

#### 4.4.5 Subsets

It is widely reported in the literature that certain attributes of the index-proxy relationship impact on the validity of proxy responses. Such attributes include the formal index-proxy relationship (the proxy is a wife/girlfriend/partner of the index) as well as informal attributes such as the length of time the index and proxy have cohabited. This is discussed in detail in the literature review in Chapter 1. As described above, the Izhevsk Family Study questionnaire collected a range of information describing such attributes, providing an opportunity here to quantitatively explore their impact on the validity of proxy responses. Subsets were then created for use in restricted analyses.

Subsets were constructed in the following way: all case proxies fulfilling the defined criteria were included; all control proxies fulfilling the criteria, and for whom a paired control interview had been obtained, were included; since the criteria in question describe the proxy respondent, the control sample was restricted according to the characteristics of the proxy, in order to maximise comparability of results, so the control sample was constructed based on the control proxy sample - all paired controls were included. In this way, the control and control proxy analyses were

conducted on exactly the same subset of individuals, removing any confounding effects of success in obtaining an interview.

Subset 1 included respondents for whom duration of index-proxy cohabitation was at least 5 years. Subset 2 comprised subjects for whom 'good' or 'extremely good' self-reported proxy knowledge of index was reported. Subset 3 was defined by frequency of proxy-index contact being at least daily. Subset 4 was defined by the index-proxy relationship, whereby the proxy was wife/girlfriend/partner (spouse) only. It was not possible to explore other types of formal index-proxy relationship due to the scarcity of respondents of other types.

#### **4.5 Exposures of interest**

The variables described below were obtained partly from questionnaire items, and partly from external data sources. Alcohol questions were chosen to be the main focus of the following analyses partly because of the context of the Izhevsk Family Study, which focuses on alcohol as a key exposure in mortality analyses, and particularly because alcohol is documented in the literature as a problematic variable with respect to proxy reporting (Chapter 1), thereby warranting in-depth exploration using this exceptional dataset. A number of other variables were selected in order to allow investigation of the way in which proxies report over a range of subject areas. These other exposures include questions on tobacco use, socio-economic status and health status.

##### **4.5.1 Questionnaire items**

###### ***Alcohol consumption and associated behaviours***

A number of surveys<sup>(87,89,96,119-125)</sup> have previously attempted to estimate alcohol consumption levels based on information obtained directly from study subjects. These have tended to focus on typical alcohol consumption (of beer, wine and spirits) and have derived measures of 'binge drinking' from data detailing pattern, frequency and amount. Traditionally used measures of frequency and amount are now considered by some researchers inadequate to describe the differences in alcohol-related mortality observed<sup>(126)</sup>. However, there are no studies in the literature



that have explicitly collected information on frequency and determinants of two important aspects of hazardous drinking in Russia: (i) periods of continuous drunkenness lasting several days (zapoï), (ii) consumption of surrogate alcohols. The term 'surrogate alcohols' refers to a group of substances containing high concentrations of ethanol but not ostensibly manufactured for drinking<sup>(127)</sup>, such as eau de cologne, alcohol-containing medicines, fluids for lighting fires, and industrial and technical spirits including window cleaner. These two behaviours are believed to be widespread, are extreme and specific to Russian situation (although not exclusively so), and previously not quantified in research. These patterns of hazardous drinking may be more strongly related to health and mortality than conventional summary measures of average alcohol consumption<sup>(124)</sup>, and the importance of obtaining accurate proxy-reported data is therefore important.

The variables from the alcohol section of the questionnaire which explores frequency, amount, pattern and indicators of alcohol consumption are itemised in Table 4.5. Following an initial literature review, this section was carefully developed, keeping questions as simple and straightforward as possible, with emphasis on easily observable behaviours, whilst trying to collect detailed information not only on pattern and amount but also on behaviours that indicate hazardous drinking (e.g. frequent hangovers). The alcohol section for the questionnaire was developed starting with standard questions on alcohol consumption drawn from a range of well-tested questionnaires, which were then piloted and analysed several times (e.g. Appendix 4) and modified to be appropriate for proxy respondents. All non-nested questions in the section on alcohol use were explored in this thesis.

**Table 4.5**      *Questions related to alcohol consumption*

<b>Code</b>	<b>Question</b>
L1	How often is beer usually drunk?
L2	How often is wine usually drunk?
L3	How often are spirits usually drunk?
L4	How often are other alcoholic substances drunk?
L5	On which day is beer usually drunk?
L6	On which day is wine usually drunk?
L7	On which day are spirits usually drunk?
L8	On which day are other alcoholic substances usually drunk?
L9	How much beer is usually drunk on one occasion?
L10	How much wine is usually drunk on one occasion?
L11	What quantity of spirits is usually drunk on one occasion?
L12	What is the maximum quantity of beer ever drunk on one occasion?
L13	What is the maximum quantity of wine ever drunk on one occasion?
L14	What are the maximum quantity of spirits ever drunk on one occasion?
L15	Does he ever drink spirits together with either beer or wine at the same sitting?
L16	Does he ever drink large quantities of spirits without also eating some food?
L17	How often does he become excessively drunk?
L18	Does he ever drink alcohol before noon?
L19	How often does he have a hangover?
L20	How often does he fail to fulfil his work obligations due to drinking alcohol?
L21	How often does he fail to fulfil his family or personal obligations due to drinking alcohol?
L22	Does he ever go to sleep at night without taking his clothes off because of being drunk?
L23	Does he ever drink alone?
L24	Does he usually drink alcohol at home or in other places?
L32	Has he been arrested because of being drunk during the past year?
L33	Does he currently drink more, less or about the same as one year ago?
L34	Does he currently drink more, less or the same as one month ago?
L36	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?
L38	Has he ever been taken to a sobering up centre?

*The response categories for each of these questions can be seen in the questionnaire reproduced in Appendix 3*

## *Tobacco use*

A number of other exposures are also the focus of the analyses presented in this thesis. Tobacco use may be a less sensitive or stigmatised behaviour, compared with alcohol consumption in this population. This may make it less prone to systematic under- or over-estimation when reported by self or proxies. The questions on tobacco use, M1-M6, are itemised in Table 4.6 on page 79. The tobacco use section for the questionnaire was also developed starting with standard questions on tobacco use drawn from a range of well-tested questionnaires, which were then piloted and analysed several times and modified to be appropriate for proxy respondents. All questions in the section on tobacco use were explored in this thesis.

*Table 4.6 Questions related to tobacco use*

<b>Code</b>	<b>Question</b>
M1	Is he a current smoker?
M2	How many years ago did he stop smoking regularly?
M3	What does he smoke most often?
M4	When he smoked, how many per day was usual?
M5	How old was he when he started smoking regularly?
M6	Have his parents ever smoked?

## *Socioeconomic/health variables*

Proxy reported questions on socio-economic position are expected to show high validity and reliability when compared with index reports and a selection of widely used questions was included in those examined in this thesis. A small selection of items on health status was also included in order to provide some indication of proxy validity when responding to questions on health. These additional questions were carefully developed in the same way as alcohol use and tobacco use questions, undergoing multiple piloting, analysis and modification in order to obtain the most valid and reliable proxy reports possible. The questions are itemised in Table 4.7 and include employment status, education, whether or not the household owns a car, the marital status of the index, whether or not the index had broken any bones in the past

year, whether he coughed in the morning, and whether he could climb a flight of stairs without becoming breathless.

*Table 4.7 Questions related to socioeconomic factors and health*

<b>Code</b>	<b>Question</b>
C14	Does his household own a car?
E15	What is his marital status?
F1	What is his level of education?
F3	Is he in regular paid employment?
J8	Is he registered disabled?
K1	Has he had any broken bones in the past year?
K2	Does he usually cough in the morning?
K3	In the past few months, could he climb up a flight up of stairs without becoming breathless?

#### **4.5.2 External sources of data**

Three external sources of data were collected in addition to questionnaire responses for all subjects, independently of interview outcome. All three sources of data are administrative sources of data, collected independently of the Izhevsk Family Study, and prior to the death of cases. Since information was recorded prior to the death of the case, it was effectively ascertained blind to case-control status. The three sources of external data are:

- Narcology Dispensary registration – had the index ever been registered for treatment at the narcology dispensary?
- Social security data – was the man in receipt of any social security (financial) benefits for disability of any kind?
- Police data – has the index been in prison?

Details of the variables collected are presented in Appendix 5.

### *Narcology Dispensary registration*

The narcology bureau is the Izhevsk city treatment centre for people with drug and/or alcohol addiction or problems. Under certain circumstances, registration is compulsory and will therefore result in an official record of registration. Such circumstances include being arrested for an alcohol-related offence or compulsory referral by a doctor at a polyclinic or hospital. Another channel for registration is voluntary registration which can be done by self, or by the family of a patient. By these channels, many of those who display hazardous drinking behaviours are registered for treatment at the narcology service at some point.

There is stigma associated with treatment at the city narcology service. Whilst compulsory registration cannot usually be avoided, those members of society who need treatment but can afford to seek it privately, often do so. This provides them with anonymity, as no record of any treatment or consultation would be kept at the public narcology service. This introduces a possible socio-economic bias into the proportion of subjects who are identified by the Izhevsk Family Study as obtaining treatment for hazardous drinking, and whilst it is not possible to estimate what proportion of those who are hazardous drinkers are actually registered at the narcology service for alcohol problems, it is assumed by those who run the Narcology Dispensary that they only see a fraction of those individuals who need treatment.

Records of narcology registration are kept at the Narcology Dispensary, and are identifiable by subject name, date of birth and address, allowing straightforward linkage to the study subjects. Whilst the sensitivity of narcology registration for alcohol problems as an indicator of hazardous drinking may not be high, the specificity is likely to be very high, and as such it can be used as an indicator of hazardous drinking behaviours, and compared with proxy reports of the same.

### *Social Security records*

The Social Security bureau holds official records of any disability benefit of which people are in receipt. This list is definitive and exhaustive, since it is the means by which payments are regulated. Since the purpose of this list is to control financial payments to citizens, it is thought to be accurate and complete. Records are again

identifiable by subject name, date of birth and address, allowing reliable record linkage. The data comprise a number of details including level of disability, date of registration. For the purposes of this investigation, the presence of a record can be compared with the questionnaire item regarding disability registration.

### *Police data*

The City of Izhevsk Police database holds all records of prison stays. This official database is unaffected by bias, since there are no means by which a record can be avoided if a person has spent time in prison. Again, records are identifiable by name, date of birth and address, allowing reliable record linkage. Presence/absence of a record can be compared with the questionnaire item regarding whether the index has ever spent time in any prison.

### **4.5.3 Autopsy data**

In addition, forensic or non-forensic autopsies were carried out for all deaths which occurred in men aged 25-54 in Izhevsk during the study period, providing detailed information on the cause of death for all study subjects. Details of the information collected are presented in Appendix 5. Information from this source is not used in this thesis.

## **4.6 Data security and confidentiality**

All data were encrypted, and no nominal data were held in the analytic data files: although contact details were essential to be able to carry out the fieldwork, only an identification number was stored within the analytic dataset. A key file linking individual identification number to personal contact and identification details was kept separately to all other data by one member of the research team, within Russia.

## **Chapter 5 Statistical methods**

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This chapter provides an overview of the methods used in analyses of the validity of proxy responses.

In the design of the study, attention was paid to ensure we collected data which allowed us to evaluate proxy responses. As described in Chapter 3, an interview was attempted with a proxy as well as with the index themselves for all study controls, and in a subset of 200 households, a ‘validation’ interview was carried out with an additional proxy. This provided multiple sets of observations on the same index subjects which could be compared in order to investigate the validity of proxy responses relative to index responses. The collection of external data allowed the validation of proxy responses against a different standard: routinely collected data sources which were ascertained independently of and prior to the interview, and therefore not subject to bias with respect to the fact of death.

### **5.1 Summary of chapter contents**

This chapter provides a discussion of the main methodologies employed in this thesis along with their advantages and disadvantages, and an explanation of the appropriateness of the selected methods in this context.

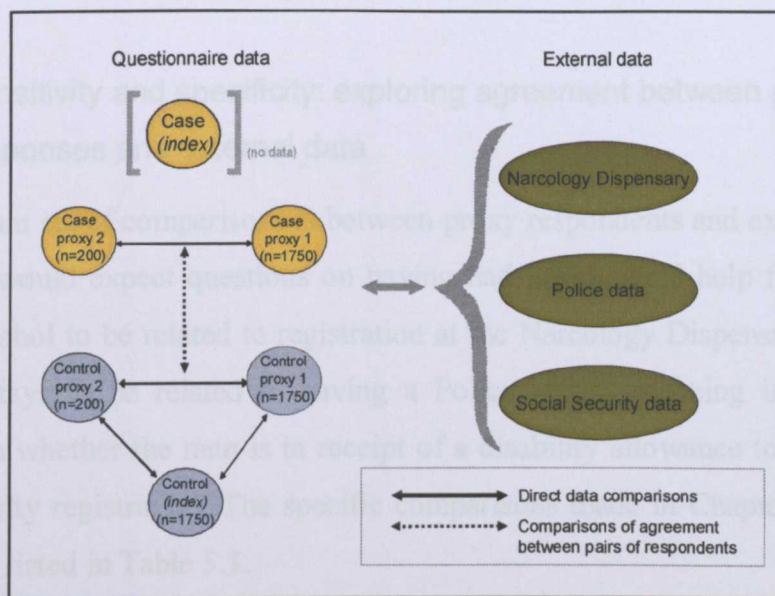
This chapter does not attempt to be an exhaustive account of every statistical method employed in this thesis: a description of the specific methods is provided within each chapter.

### **5.2 Key validation comparisons**

Figure 5.1 shows the comparisons which are the main subject of this thesis. For both case and control subjects, the questionnaire data gathered from proxies and indexes (controls only) can be compared with a range of external data sources, the Narcology Dispensary, Police records and Social Security data. A range of comparisons between types of respondents may be made: among controls, the questionnaire data gathered from proxy1 and proxy2 can be compared with the index questionnaire data, and with each other. For case subjects there is no index interview, but responses

from proxy1 may still be compared with proxy2 for the validation sample of 200 households. Finally, comparisons in agreement between different types of *pairs* of respondents may also be made – proxy1 versus proxy2 in cases compared with controls, and proxy1 versus the index compared with proxy2 versus the index within control households.

Figure 5.1 Overview of validation comparisons within the Izhevsk Family Study



### 5.3 Statistical methods

The analyses carried out in the following chapters use different types of data (questionnaire, external data) to address several research questions, which require a range of statistical methods.

A first set of analyses will be carried out in Chapter 6 to investigate the validity of proxy responses with respect to external, non-questionnaire sources of data. Sensitivity, specificity and odds ratios are used in this chapter. The methods are described in section 5.3.1.

A second set of analyses presented in Chapter 7 compare proxy data with index data among controls. Cohen's kappa coefficient is used to examine index-proxy agreement, as described in section 5.3.2, and a loglinear model developed by



Agresti<sup>(128)</sup> is used to formally compare agreement between pairs of respondents. This is described in section 5.3.3.

A third set of analyses presented in Chapter 8 also use validation interviews to examine the impact of index-proxy relationship attributes on data quality, using Agresti's loglinear model to formally compare the agreement between different types of respondent pairs, as described in section 5.3.3.

All analyses were carried out using STATA version 8.2. Texas, USA.

### 5.3.1 Sensitivity and specificity: exploring agreement between proxy responses and external data

One important set of comparisons is between proxy respondents and external data. *A priori*, one would expect questions on having had professional help for an alcohol problem alcohol to be related to registration at the Narcology Dispensary, questions on prison stays to be related to having a Police record of being in prison, and questions on whether the man is in receipt of a disability allowance to be related to Social Security registration. The specific comparisons made in Chapter 6 are based on the items listed in Table 5.1.

**Table 5.1** *Questionnaire items and the external data sources against which they were compared*

External data	Questionnaire item
Police record of a prison stay	Has he ever been in any kind of prison?
Social Security registration as disabled	Is he registered disabled?
Registration at the Narcology Dispensary	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?

Whilst the external data items and questionnaire items being compared are related, they are not necessarily measuring the same thing. The external data source is equivalent to an outcome, whilst the questionnaire response can be viewed as analogous to the outcome of a screening test. It is possible to quantify these associations by examining the proportion of subjects who do (do not) have an

external data record for whom a positive (negative) questionnaire response is obtained, i.e. sensitivity/specificity calculations, as illustrated by Table 5.2.

*Table 5.2 Example association between questionnaire responses and external data records*

		External data		sensitivity	specificity	OR
		Yes	No			
Questionnaire response	Yes	a	b	$a/(a+c)$	$d/(b+d)$	$(a/c)/(b/d)$
	No	c	d			

Sensitivity is defined as the proportion of true positives correctly identified by a test ( $a/(a+c)$ ) whilst specificity is defined as the proportion of true negatives correctly identified by a test<sup>(129)</sup> ( $d/(b+d)$ ). Sensitivity is therefore an indicator of how well those who have the outcome (external data) are correctly identified by a positive response to a questionnaire item, whilst specificity is an indicator of how well those who do *not* have the outcome (external data) are correctly identified by a negative response to a questionnaire item. In addition, it is possible to calculate an odds ratio representing the magnitude of each association as the cross product ratio of this two by two table.

Sensitivity and specificity calculations are an appropriate means of evaluating agreement as an ‘absolute’ measure of the performance of proxy responses. Odds ratios provide a simply summary of the overall strength of association between the questionnaire items and outcomes - which can be derived from the raw data, or from sensitivity and specificity.

In Chapter 6, assessment of agreement of proxy data with external data sources will be carried out using a combination of these two methods; comparisons of sensitivity and specificity, and odds ratios of questionnaire items, which are obtained using logistic regression and presented adjusted for age group. The associations between control proxy data and external data are examined alongside the associations between control data and the same external data. As a comparative frame of reference, the use of self-reports is useful in this context, despite what is known about the questionable validity of self-reports, particularly with respect to alcohol consumption<sup>(49,51,53,56)</sup>.

Since no attempt is being made to evaluate agreement between multiple observations of exactly the same exposure, Cohen's kappa coefficient would not be an appropriate measure for assessment of agreement in this context.

### 5.3.2 Cohen's kappa coefficient: exploring agreement between two respondents

Cohen's kappa coefficient is a summary statistic which assesses the level of concordance between two observers beyond that expected by chance alone for categorical variables. It represents the extent to which agreement is greater than that expected by chance, as a percentage of the maximum possible improvement over chance. It can be used for binary, ordinal or nominal response categories.

**Table 5.3** Example table expressing the frequency of responses to a given question provided by two classes of rater, A and B

		Raters of class B				Total
		(j)				
		1	2	3	4	
Raters of class A (i)	1	$n_{1,1}$	$n_{1,2}$	$n_{1,3}$	$n_{1,4}$	$N_{1..}$
	2	$n_{2,1}$	$n_{2,2}$	$n_{2,3}$	$n_{2,4}$	$N_{2..}$
	3	$n_{3,1}$	$n_{3,2}$	$n_{3,3}$	$n_{3,4}$	$N_{3..}$
	4	$n_{4,1}$	$n_{4,2}$	$n_{4,3}$	$n_{4,4}$	$N_{4..}$
Total		$N_{.,1}$	$N_{.,2}$	$N_{.,3}$	$N_{.,4}$	$N$

The formula for kappa is as follows.

$$\text{Kappa} = \frac{(\text{observed \% exact agreement}) - (\text{expected \% exact agreement})}{1 - (\text{expected \% exact agreement})}$$

Expected frequency can be calculated for any cell in the usual way, by dividing the product of the row and column totals by the table total, N. Thus for cell  $n_{2,3}$ , the expected frequency is  $(N_{2..} * N_{.,3})/N$ . When calculating exact agreement, the cells considered are those where  $i=j$ , i.e.  $n_{1,1}$ ,  $n_{2,2}$ ,  $n_{3,3}$ ,  $n_{4,4}$  – the cells on the diagonal. In this case, the coefficient obtained is known as *unweighted* kappa, as all disagreements (cells off the main diagonal) are ignored (given a weighting of 0). For questions with ordinal response categories, a weighted coefficient can be obtained which allocates greater weight to more similar responses, the most similar being on

the main diagonal, and the least similar lying in the discordant corners, i.e.  $n_{1,4}$  and  $n_{4,1}$  in Table 5.3. Weightings determine the importance with which disagreements are treated and may be assigned to the data by a user-defined matrix or using one of two prerecorded options available in STATA. One of the prerecorded weighting options is used here: weightings are calculated using the following formula for the weight for the cell assigned to row  $i$ , column  $j$ , where there are  $g$  categories:

$$w_{ij} = 1 - \frac{|i - j|}{g - 1}$$

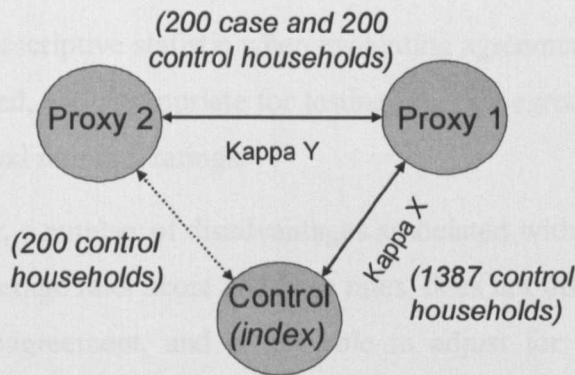
The kappa coefficient takes a maximum value of 1 for perfect agreement, 0 for agreement no better than chance, and less than one for agreement worse than that expected by chance: high kappa values indicate high agreement, low kappa values indicate low agreement at an individual level.

Specifically, agreement is interpreted in accordance with the scheme developed by Landis and Koch<sup>(67)</sup>: <0, poor; 0.00–0.20, slight; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; >0.8, almost perfect. To aid interpretation of kappa coefficients, values should be examined alongside frequency tables of the distribution of questionnaire variables<sup>(129)</sup>, which are provided in *appendix 6*. Missing values were excluded from calculations (no response, don't know). In STATA, Kappa is obtained using the STATA command *kap*. Confidence intervals are obtained using the standard STATA command *kapci* which uses an analytical method for 2x2 tables, and bootstrap methods otherwise.

### ***Kappa and the Izhevsk Family Study***

Figure 5.2 is a reduced version of Figure 5.1, and provides a schematic overview of the respondent types interviewed in this study, and the different combinations of respondents that can be compared in order to investigate agreement. Kappa Y indicates proxy-proxy agreement, which can be obtained for both case and control households where 2 proxies are interviewed. Kappa X describes index-proxy agreement which can be obtained in all control households. Kappa X cannot be obtained in case households since no index is interviewed.

Figure 5.2 Schematic diagram of the kappa coefficients which can be obtained in different households



The numbers presented here correspond to subsets described in Chapter 4

There are thus two approaches to investigating the impact of the index-proxy relationship on quality of proxy response use Cohen's kappa coefficient.

1. Calculation of kappa X coefficients for all control households, stratifying by informant type. This will provide a broad indication of the extent of index-proxy agreement for different proxy types for questions examined, but does not make any adjustment for characteristics or behaviour of the index, which is likely to influence proxy responses. (Chapter 7)
2. Calculation of kappa Y coefficients. This analysis will be carried out for households which provide responses from a spouse as proxy 1 and the next best available respondent as proxy 2. These kappa coefficients demonstrate to what extent proxies within one household agree with each other. This analysis cannot indicate which proxy type is better, only the extent to which proxy types differ significantly from each other in the responses they provide about the same index for specific questions. (Chapter 8).

It would theoretically be possible to obtain Cohen's kappa coefficient to describe the agreement between the index and proxy 2 in 200 control households, which could be used to examine validity of responses provided by proxies of different types in

households where more than one proxy was interviewed. However, since there is no satisfactory framework for comparing kappa statistics (see below), different methods were employed for this, as discussed in section 5.3.3.

### *Advantages/disadvantages of kappa*

Kappa is a useful descriptive statistic when evaluating agreement between two raters. It is easily calculated, and appropriate for testing whether agreement exceeds chance ratings for binary and nominal ratings.

There are, however, a number of disadvantages associated with kappa. Firstly, kappa is influenced by average rater score and base rates, does not distinguish among types and sources of disagreement, and is not able to adjust for any other exposures. Additionally, whilst guidelines such as those developed by Landis and Koch<sup>(67)</sup> are helpful when using kappa to describe agreement, these guidelines are arbitrary, and in fact kappa may be low even when there are high levels of agreement and when individual ratings are accurate<sup>(130-133)</sup>. There are further disadvantages associated with the use of kappa. The loss of information by summarizing a table with a single number, and the fact that kappa is affected by the form of the marginal distributions mean that whilst kappa is useful as a descriptive variable, there is no satisfactory framework for formally comparing kappa values, i.e. the comparison of pairs of raters.

### **5.3.3 Loglinear models: comparing the agreement of pairs of respondents**

For evaluation of the relative extent of agreement between pairs of raters, kappa is insufficient since it does not lend itself to formal comparisons among groups. There are a number of established approaches to modeling agreement that overcome the inadequacies of kappa, of which the use of loglinear models is one. In a loglinear model, Poisson regression is used to model the log of the expected value of table cell counts.

The following 5 \* 5 table represents pairwise agreement of raters of class A versus class B for a given question with five ordinal response categories. The frequency of each type of response is represented by  $n(i,j)$  where  $i$  is the response given by rater A, and  $j$  is the response given by rater B.

Table 5.4 Example: frequency of responses (i,j) to a given question provided by two classes of rater, A and B

		Raters of class B				
		(j)				
		1	2	3	4	5
Raters of class A (i)	1	<u>n<sub>1,1</sub></u>	n <sub>1,2</sub>	n <sub>1,3</sub>	n <sub>1,4</sub>	n <sub>1,5</sub>
	2	n <sub>2,1</sub>	<u>n<sub>2,2</sub></u>	n <sub>2,3</sub>	n <sub>2,4</sub>	n <sub>2,5</sub>
	3	n <sub>3,1</sub>	n <sub>3,2</sub>	<u>n<sub>3,3</sub></u>	n <sub>3,4</sub>	n <sub>3,5</sub>
	4	n <sub>4,1</sub>	n <sub>4,2</sub>	n <sub>4,3</sub>	<u>n<sub>4,4</sub></u>	n <sub>4,5</sub>
	5	n <sub>5,1</sub>	n <sub>5,2</sub>	n <sub>5,3</sub>	n <sub>5,4</sub>	<u>n<sub>5,5</sub></u>

Exact agreements (on the diagonal) are underlined. Near agreements (one category apart) and exact agreements are shaded in groups of four cells, whilst unshaded cells represent pairs of observations which differ by more than one category. Pairs of observers who differ in their responses by one category or less are those which may be reasonably considered to provide similar responses with respect to each other. Considering these groups of shaded cells, the association between raters of class A and class B when, for example, i=2, can be expressed in terms of the following odds ratio:

$$\frac{\text{the odds that A scores 3 vs A scores 2 | when B scores 3}}{\text{the odds that A scores 3 vs A scores 2 | when B scores 2}}$$

$$= \frac{n_{3,3} / n_{2,3}}{n_{3,2} / n_{2,2}} = \frac{n_{2,2} * n_{3,3}}{n_{2,3} * n_{3,2}}$$

Or more generally :  $\theta_{i,i} = \frac{n_{i,i} * n_{i+1,i+1}}{n_{i,i+1} * n_{i+1,i}}$

A particular loglinear model described by Agresti<sup>(128)</sup> and called the ‘agreement plus uniform association’ model, predicts the log cell counts used to derive this odds ratio by an amalgamation of Tanner and Young’s model and the uniform association model<sup>(133,134)</sup>.

$$\log n_{ij} = \mu + \lambda_i^A + \lambda_j^B + \beta u_i u_j + \delta * s(i = j)$$

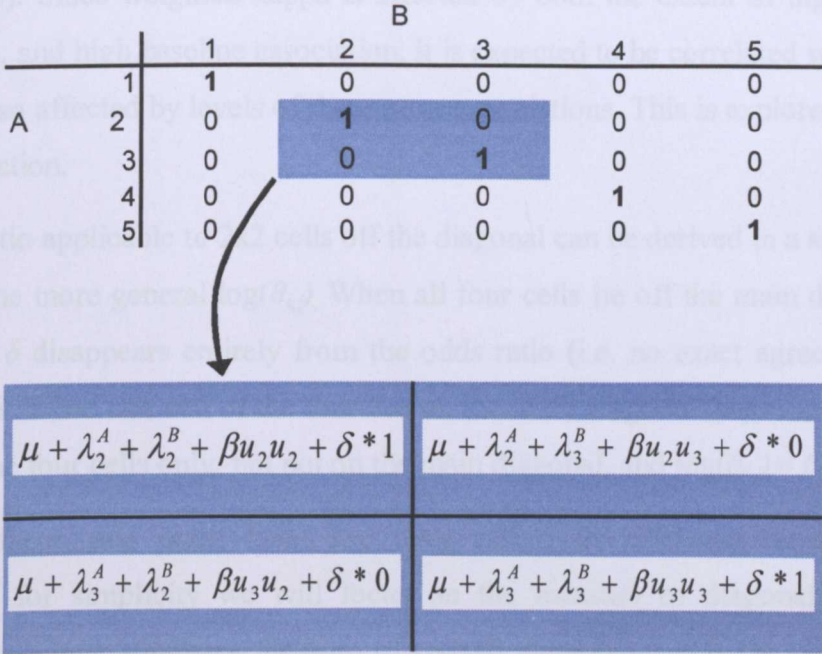


For a question with  $k$  ordinal response categories,  $i, j$  are fixed scores  $1, 2, \dots, k$  assigned to the response categories. In order to assess agreement between two classes of rater, A and B, a model of this form, predicting the expected frequency (outcome  $n_{ij}$ ) of rating  $i$  by A and rating  $j$  by B is fit to the data. The model contains a number of parameters. The  $\lambda$  terms represent the main effects of the two classes of rater, whilst parameters ' $\delta$ ' and ' $\beta$ ' describe components of the agreement between them.  $\beta$  represents the 'baseline' association between classes of rater excluding the exact agreement on the diagonal, by quantifying the dependence between off-diagonal rater scores  $i$  and  $j$ , where  $u_i = i$  and  $u_j = j$ .  $\beta$  is particularly important with ordinal rating, as typically there is a general association between ordinal scores with, for example, high scores being associated (though not necessarily in exact agreement). Unlike kappa,  $\beta$  is unaffected by different average rater scores since the model controls for the main effects of ratings  $i$  and  $j$  ( $\lambda$ ). The term  $\delta * s(i=j)$  is equal to  $\delta$  if  $i=j$ , and 0 otherwise, as determined by the indicator 's', which takes the value 1 for cells on the main diagonal, and 0 everywhere else (see Figure 5.3).  $\delta$  represents the extent of exact agreement (on the diagonals) *beyond* that expected from any baseline association between raters' classifications, i.e. from associations occurring off the diagonal. With nominal categories, where we expect  $\beta=0$ ,  $\delta$  describes the agreement in a similar way to unweighted kappa coefficients, concentrating on exact agreement only in the absence of any baseline association. Where there is baseline association, exact (diagonal) agreement comprises the effect of both the baseline association represented by  $\beta$  and the increment  $\delta$  due to exact agreement.

In the model above, agreement is thus partitioned into three components<sup>(128)</sup>: chance, baseline (represented by  $\beta$ ) both of which apply to all cells, plus an effect applicable only to diagonal cells (represented by  $\delta$ ) which is an increment reflecting agreement in excess of the first two components. The extent to which overall agreement exceeds chance is thus given by a combination of the baseline and specifically diagonal effects. The predicted log cell counts in a square contingency table according to Agresti's loglinear model are illustrated by Figure 5.3.



Figure 5.3 Distribution of indicator 's' in a 5\*5 table and corresponding predicted log cell counts (log n<sub>ij</sub>)



Following Figure 5.3, it is possible to derive the odds ratio  $\theta_{i,i}$  for any group of 4 cells which lie on the main diagonal, using the predicted log cell counts from Agresti's loglinear model.

$$\begin{aligned}
 \log \theta_{i,i} &= \log \left( \frac{n_{i,i} * n_{i+1,i+1}}{n_{i,i+1} * n_{i+1,i}} \right) \\
 &= \begin{aligned}
 &+ \log n_{i,i} && = +\mu + \lambda_i^A + \lambda_i^B + \beta u_i^2 + \delta * 1 \\
 &+ \log n_{i+1,i+1} && = +\mu + \lambda_{i+1}^A + \lambda_{i+1}^B + \beta u_{i+1}^2 + \delta * 1 \\
 &- \log n_{i,i+1} && = -\mu - \lambda_i^A - \lambda_{i+1}^B - \beta u_i u_{i+1} - \delta * 0 \\
 &- \log n_{i+1,i} && = -\mu - \lambda_{i+1}^A - \lambda_i^B - \beta u_{i+1} u_i - \delta * 0
 \end{aligned} \\
 &= \beta u_i^2 + \beta u_{i+1}^2 - 2\beta u_i u_{i+1} + 2\delta \\
 &= \beta (u_{i+1} - u_i)^2 + 2\delta \quad \text{but} \quad u_{i+1} - u_i = (i+1) - i = 1 \\
 \therefore \log \theta_{i,i} &= \beta + 2\delta
 \end{aligned}$$

The local odds ratio given previously,  $\theta_{i,i}$  can therefore be expressed in terms of the exact agreement and association parameters.  $\log(\theta_{i,i})$  is equal to  $\beta + 2\delta$ , so  $\theta_{i,i} = \exp(\beta + 2\delta)$ . Since weighted kappa is affected by both the extent of high diagonal association, and high baseline association, it is expected to be correlated with  $\log(\theta_{i,i})$  which is also affected by levels of these same associations. This is explored further in the next section.

An odds ratio applicable to 2x2 cells off the diagonal can be derived in a similar way, to obtain the more general  $\log(\theta_{i,j})$ . When all four cells lie off the main diagonal ( $|i-j|>1$ ,  $s=0$ ),  $\delta$  disappears entirely from the odds ratio (i.e. no exact agreement), and  $\log(\theta_{i,j}) = \beta$ . When one cell of the four lies on the main diagonal ( $|i-j|=1$ ),  $\delta$  is present in one of the four cells only, but not on the main diagonal, and  $\log(\theta_{i,j}) = \beta - \delta$ .

Although these two other local log odds ratios are also measures assessing agreement, for simplicity we will focus on the measure of diagonal agreement  $\log(\theta_{i,i})$  as a single summary measure of overall agreement: it is the most suitable comparator for weighted kappa, and also has the advantage of incorporating the baseline association. Exact or near agreement is arguably of greater intrinsic interest in this context. Henceforth we will drop the subscripts and assume  $\theta = \theta_{i,i}$ .

Having modeled the agreement between pairings of two specific classes of rater in this way, a formal comparison between two different *pairings* of classes of rater can be obtained by modeling the difference in agreement between two two-way tables I and II.

Table I – rater A and rater B scoring index X

		Raters of class B				
		(j)				
		1	2	3	4	5
Raters of class A (i)	1	$n_{1,1}$	$n_{1,2}$	$n_{1,3}$	$n_{1,4}$	$n_{1,5}$
	2	$n_{2,1}$	$n_{2,2}$	$n_{2,3}$	$n_{2,4}$	$n_{2,5}$
	3	$n_{3,1}$	$n_{3,2}$	$n_{3,3}$	$n_{3,4}$	$n_{3,5}$
	4	$n_{4,1}$	$n_{4,2}$	$n_{4,3}$	$n_{4,4}$	$n_{4,5}$
	5	$n_{5,1}$	$n_{5,2}$	$n_{5,3}$	$n_{5,4}$	$n_{5,5}$

Table II – rater C and rater D scoring index Y

		Raters of class D				
		(j)				
		1	2	3	4	5
Raters of class C (i)	1	$n_{1,1}$	$n_{1,2}$	$n_{1,3}$	$n_{1,4}$	$n_{1,5}$
	2	$n_{2,1}$	$n_{2,2}$	$n_{2,3}$	$n_{2,4}$	$n_{2,5}$
	3	$n_{3,1}$	$n_{3,2}$	$n_{3,3}$	$n_{3,4}$	$n_{3,5}$
	4	$n_{4,1}$	$n_{4,2}$	$n_{4,3}$	$n_{4,4}$	$n_{4,5}$
	5	$n_{5,1}$	$n_{5,2}$	$n_{5,3}$	$n_{5,4}$	$n_{5,5}$

Focusing on the chosen summary measure of overall agreement, the odds ratio  $\theta$ , or more conveniently  $\log(\theta) = \beta + 2\delta$ , then the *difference* between the agreement of raters of class A and class B, compared with the agreement between raters of class C and class D is given by  $\log(\theta_I) - \log(\theta_{II})$ . This term,  $\log(\theta_I) - \log(\theta_{II})$ , will be denoted as  $\tau$ , and is obtained by fitting the model to both sets of data simultaneously, and incorporating interaction terms as follows:

$$\log n_{ij} = \mu + \lambda_i^A + \lambda_j^B + \beta u_i u_j + \delta * s(i = j)$$

$$+ \gamma_0.id + \gamma_1.id * \lambda_i^A + \gamma_2.id * \lambda_j^B + \gamma_3.id * u_i u_j + \gamma_4.id * s(i = j)$$

where ‘id’ is an indicator that takes the value 1 for one set of raters (Table I), and 0 for the second set (Table II).  $\tau$  is then obtained from the relevant interaction terms:  $\tau = \log(\theta_I) - \log(\theta_{II}) = \gamma_3 + 2\gamma_4$ , which is the difference in  $\beta + 2\delta$  between group I and group II.

A test of the null hypothesis that the difference,  $\tau = 0$ , indicates whether there is statistical evidence of a difference in the extent of agreement between the two types of pairing; and therefore a  $\tau$  whose confidence interval includes 0 represents a

situation where two pairs of rater classes do not statistically differ from one another<sup>(128,135,136)</sup> in terms of their agreement. It must be noted that in principle exact agreement between two pairs of classes of rater could be very similar even though the  $\beta$  and  $\delta$  parameters were each statistically different. However, the resultant exact agreement is of more practical importance than these component parameters taken separately, so it is of more interest to restrict the comparison to the former.

In addition to being applied to comparisons of pairs of independent classes of rater, in Chapter 8, this method is used to compare two pairs of classes of rater that share a common respondent, i.e. Table I above could contain the frequency of observations by raters of class A and class B, whilst Table II could contain the frequency of observations by raters of class A and class D (rather than C and D). Despite sharing a common set of raters, using interaction terms in the model to assess the difference in agreements is not affected by the common margin in Tables I and II, since the difference in log likelihood (with change of degrees of freedom due just to the interaction terms) is unaffected by problems the common margin gives in assigning total log likelihood and degrees of freedom. However, in using data from raters of class A twice within one model, the agreements between the two sets of pairs are not independent and are likely to be more highly correlated than in the former scenario, as factors driving the agreement, or lack of agreement between A and C may plausibly act in similar ways on the agreement between A and D for each set of raters. Ignoring the common use of raters of class A and the resultant concordance in agreements may lead to conservative estimates of  $\tau$ .

#### 5.3.4 Relation of log-linear estimate to kappa

It is helpful to explore how the parameters from Agresti's model relate to kappa values. Using a sample of data from the Izhevsk Family Study, scatter plots of unweighted kappa against  $\delta$  for nominal and binary questions, and weighted kappa against the combined estimate  $\beta + 2\delta$ , i.e.  $\log(\theta)$  for ordinal questions, illustrate how these two different approaches to assessing agreement compare with one another. The comparisons were made between responses from proxy1 and proxy2 within 200 case households across a range of questions.



It is clear from Figure 5.4, which represents each question by a point in the scatter plot, that there is a correlation between  $\delta$  and unweighted kappa for nominal and binary questions. It is reassuring that those questions which are indicated to have high agreement by kappa also emerge as having high agreement when Agresti's model is applied. There is, however, less than perfect agreement, and these residuals reflect the different approaches employed in constructing the two measures.

Examination of Figure 5.5 is similarly reassuring in the respect that the estimate  $\log(\theta)$ , chosen to represent the agreement between two sets of raters is very closely correlated with weighted kappa for ordinal questions,  $\log(\theta)$  is employed in making these types of comparisons in Chapter 7 and Chapter 8.

Figure 5.4 Scatter plot of  $\delta$  against unweighted kappa, comparing responses from proxy1 and proxy2 among 200 case households for a range of nominal and binary questions

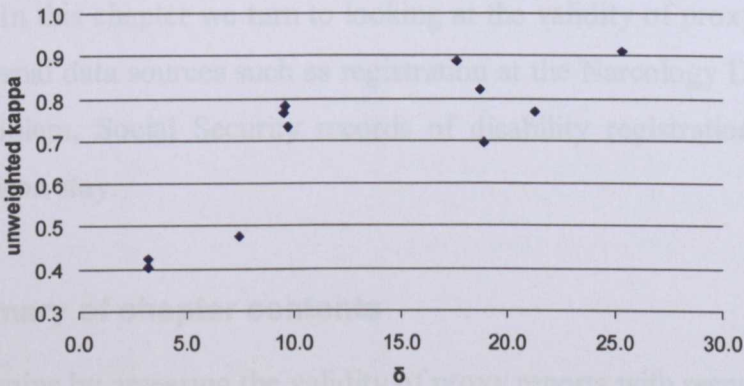
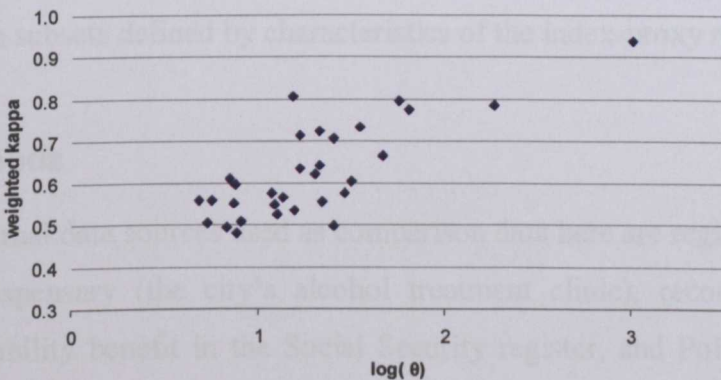
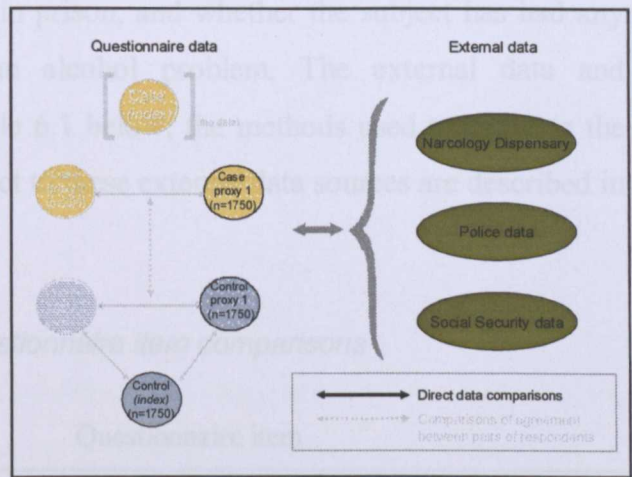


Figure 5.5 Scatter plot of  $\log(\theta)$  against weighted kappa, comparing responses from proxy1 and proxy2 among 200 case households for a range of ordinal questions



# Chapter 6 Are proxies valid? Using external data to validate control proxy and case proxy responses

In the absence of a 'gold standard', a number of approaches to assess whether proxy responses are valid may be used. One of these is to compare proxy questionnaire responses with non-questionnaire ('external') data sources which measure similar behaviours or attributes to the



questionnaire. In this chapter we turn to looking at the validity of proxy respondents relative to external data sources such as registration at the Narcology Dispensary for an alcohol problem, Social Security records of disability registration, and Police records of a prison stay.

## 6.1 Summary of chapter contents

This chapter begins by assessing the validity of proxy reports with respect to external data sources in the whole dataset. It then examines differences between case proxy and control proxy respondents in the reporting of questionnaire items related to external data. Finally, it assesses the impact of characteristics of the index-proxy relationship on the validity of proxy reports in this context by examination of associations in subsets defined by characteristics of the index-proxy relationship.

## 6.2 Methods

The three external data sources used as comparison data here are registration with the Narcology Dispensary (the city's alcohol treatment clinic), records of being in receipt of disability benefit in the Social Security register, and Police records of a

prison stay. These data are described in detail in Chapter 4. Such routinely collected external data have merit as reference data in this context since they are prospectively collected, independently of the research being carried out, prior to the death of the case and therefore ascertained blind with respect to case-control status. The questionnaire items examined include questions on whether the subject is in receipt of any disability benefit, time spent in prison, and whether the subject has had any professional help or advice for an alcohol problem. The external data and questionnaire items are listed in Table 6.1 below; the methods used to evaluate the quality of proxy responses with respect to these external data sources are described in Chapter 5.

**Table 6.1** *External data and questionnaire item comparisons*

<b>External data</b>	<b>Questionnaire item</b>
Police record of a prison stay	Has he ever been in any kind of prison? (Questionnaire item F17)
Social Security registration as disabled	Is he registered disabled? (Questionnaire item J8)
Registration at the Narcology Dispensary	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem? (Questionnaire item L36)

### ***Distribution of variables***

The distribution of questionnaire item responses and external data among case and control index subjects for whom a successful proxy interview was conducted was obtained using simple cross tabulations of these variables against index type.

### ***Evaluation of association between questionnaire items and external data***

In order to investigate the strength of association between each exposure variable and the relevant external data, sensitivity and specificity were obtained, and odds ratios (OR) and their confidence intervals were calculated for control, control proxy and case proxy respondents. Of particular interest was to investigate how external data

are associated with control versus control proxy data. Where measures of effect differ in favour of a bigger OR when using proxy data, indicating stronger association between questionnaire and external data, or less dramatically, where the estimates do not differ, this suggests that proxies may provide data that is as valid as the controls themselves.

In order to explore whether particular attributes of the index-proxy relationship are important in terms of the validity of proxy responses, all analyses were repeated restricting to subsets defined by attributes of the index-proxy relationship, as detailed in Chapter 4.

### **6.3 Results**

Before considering the association of questionnaire responses with external data, the distribution of subjects was considered on aggregate. The expectation is that there are similar proportions of indexes reported to display certain behaviours as having records in external data sources. Examination of this distribution is informative in the interpretation of subsequent analyses. The crude distribution of the questionnaire-derived exposures and the external data against which they are analysed are presented in Table 6.2.

The two sources of data on disability registration show that among controls considered in this chapter, the vast majority of men were not reported by a proxy to be in registered as disabled (7.1%), and a similarly small number were found to be registered within Social Security records. Less than 5% of men were reported by their proxies to have ever spent any time in prison, and almost exactly the same percentage were found within the police database to be recorded as having had one or more prison stays. Finally, in the examination of alcohol-related items, it was found that a very small proportion of men were registered at the Narcology Dispensary (3.7%). However, larger numbers of men were reported to have ever had professional help for an alcohol problem (14.2%).

Among cases, a similar pattern of these markers was observed, with the lowest proportion found to have the prison related items and the highest proportion displaying alcohol-related behaviours. However, a much higher percentage of cases



than controls was reported to display these markers in every instance. Around ¼ of cases were found to have each of the disability-related items and approximately double the number of cases as controls were reported to have been in prison or were found to have a police record of a prison stay. Finally, much higher proportions of cases than controls were reported to display the alcohol-related behaviours, with 16.7% found to be registered at the Narcology Dispensary and 30.7% reported to have received professional help or advice for an alcohol problem.

**Table 6.2** *Distribution of index subjects by proxy report (questionnaire data) and from external data sources by case-control status<sup>b</sup>*

Questionnaire/external data item		Controls		Cases	
		n	%	n	%
<b>Disability-related items</b>					
Is he registered disabled	no	1289	92.9	928	71.1
	yes	98	7.1	374	28.7
	missing	0	0.0	3	0.2
	Total	1387	100.0	1305	100.0
*Social Security registration as disabled?	no	1315	94.8	984	75.4
	yes	72	5.2	321	24.6
	missing	0	0.0	0	0.0
	Total	1387	100.0	1305	100.0
<b>Police record/prison stay</b>					
Has he ever been in any kind of prison	no	1,315	94.8	1,072	82.1
	yes	67	4.8	225	17.2
	missing	5	0.4	8	0.6
	Total	1,387	100.0	1,305	100.0
*Police data - has he ever been in prison?	no	1,327	95.7	1,125	86.2
	yes	60	4.3	180	13.8
	missing	0	0.0	0	0.0
	Total	1,387	100.0	1,305	100.0
<b>Alcohol-related items</b>					
Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	no	1179	85.0	886	67.9
	yes	197	14.2	401	30.7
	missing	11	0.8	18	1.4
	Total	1387	100.0	1305	100.0
*Narcology Dispensary registration?	no	1,336	96.3	1,087	83.3
	yes	51	3.7	218	16.7
	missing	0	0.0	0	0.0
	Total	1,387	100.0	1,305	100.0

\* external data item

<sup>b</sup> The data presented in this table describes all subjects for whom a successful interview was obtained, except for those subjects excluded due to failure for interviews to be carried out according to the Izhevsk Family Study protocol. These exclusions are described in detail in Chapter 4.

### 6.3.2 Agreement between questionnaire derived data and external data

Sensitivity, specificity and OR describing the relationships between questionnaire-derived data and external data are presented in Table 6.3.

Since having a record in the Social Security bureau is an administrative necessity in order to be in receipt of invalidity benefit, sensitivity is expected to be near 100%, with only a small number of disagreements arising because of data being incomplete or incorrect. For similar reasons, specificity is expected to also approach 100%. This is indeed what is observed among both controls and control proxies. Since the absolute number of subjects who are registered disabled is low and the number of subjects who are registered disabled but reported not to be by questionnaire responses is also very low, sensitivity is close to 1 in all instances, and the ORs obtained are very high with very wide confidence intervals. Thus, the difference in point estimates for ORs obtained here are rather misleading (and illustrate how sensitive ORs are to small changes in distribution) since the high values observed for control proxies and controls are largely driven by the very small number of subjects who are registered but responded negatively to the questionnaire item, and the large number of subjects who are not registered (and were correctly reported as such). The distributions reported by control proxies and controls are identical, suggesting that control proxies are as valid as controls in their reporting of these data.

The expectation is that these associations be similar among both cases and controls, since there is little reason why the relationship between questionnaire and external data would be greatly affected by the higher prevalence of disability among cases, beyond the possibility of a tendency for case proxies to more often incorrectly report the case to be disabled, due to poorer health in general in this group of indexes. Therefore for these data, any differences between case proxy and control proxy measures would be to some extent indicative of a reporting bias attributable to the fact of death. There is in fact little indication of bias in the reporting of this question between case and control proxies with respect to Social Security registration.

In considering data regarding any time spent in prison, similar expectations apply: all men who have spent time in prison should be recorded as having done so in Police records and this should be reflected in questionnaire reports of having had a prison

stay. However, it is not certain that proxies would be aware of all prison stays, since the index may choose to try and hide these occurrences if possible, and for similar reasons, indexes may choose to lie about such events in interviews. There is also the possibility of misinterpretation of the questions, whereby a very short stay which results in a police record is not acknowledged by respondents as requiring a positive answer to the questionnaire item. Therefore it is anticipated that sensitivity will be below 100%. The results are in accordance with this supposition, with sensitivity values for all respondents being less than 100%. However, if a person has not spent time in prison, it is unlikely that they or their proxies will answer that they have, so the logical expectation is for specificity to approach 100% provided that both questionnaire data and external data are complete. This is indeed what is observed.

There is little variation between control and control proxy sensitivity or specificity, indicating that proxies are as valid as controls with respect to reporting this question, a finding supported by the similar magnitude of the ORs obtained using control proxy versus control data. Case and control proxy reports of this question are similar with respect to police records, in terms of the magnitude of the observed OR, sensitivity and in particular, specificity, suggesting that case proxies are similarly valid for this question and there is little reporting bias attributable to the fact of death of the index.

The external data on Narcology Dispensary registration captures all those who have been registered at the Narcology Dispensary for help or advice for an alcohol problem, and accordingly should be related to questionnaire reports of having received professional help or advice for an alcohol problem. It is indeed observed that the ORs are substantial and similar for controls and control proxies, but lower than those observed for police and social security data. All those who are registered at narcology should report having obtained professional help; therefore sensitivity should be 100%, although not all those who have received professional help will be registered since professional help can be obtained elsewhere. Therefore specificity may logically be less than 100%. We would therefore expect sensitivity to be greater than specificity for this question, whereby a smaller proportion of those registered fail to report receiving professional help than the proportion of those *not* registered who *do* report receiving professional help. However, this is not observed: around

30% of those who are registered at narcology do not report having received professional help, and more than 10% of those who are not registered report having received professional help. These findings are more revealing of the type of service provided by narcology and its population coverage, than of the quality of proxy responses with respect to these data, although it is also possible that stigma associated with registration at the Narcology Dispensary could affect index and proxy reporting of the relevant question, with implications for both sensitivity (likely to be decreased) and specificity (likely to be increased). However, the similarity of sensitivity, specificity and ORs obtained using control and control proxy data suggests that proxy respondents are reporting in a similar way to controls in answering this question.

There is little difference observed between case and control proxy sensitivity or specificity, which is reflected in the ORs, whose point estimates differ but whose confidence intervals overlap almost entirely.

**Table 6.3** Association of questionnaire variables with external data illustrated by odds ratios, and by sensitivity/specificity of the questionnaire to predict the external data registration where appropriate

Questionnaire Item	Respondent	y	n	Sensitivity	Specificity	OR (95% CI)
<b>External data: Social Security registration</b>						
Is he registered disabled?	Control (index)	y 49	n 22	0.94	0.98	791.4 (101.9,6145.0)
		y 3	n 1066			
	Control proxy	y 49	n 22	0.94	0.98	791.4 (101.9,6145.0)
		y 3	n 1066			
	Case proxy	y 310	n 64	0.97	0.93	557.0 (126.6,2452.0)
		y 8	n 920			
<b>External data: Police records</b>						
Has he ever been in any kind of prison?	Control (index)	y 41	n 10	0.63	0.99	181.9 (59.5,556.3)
		y 24	n 1065			
	Control proxy	y 38	n 12	0.67	0.99	177.8 (58.9,537.3)
		y 19	n 1067			
	Case proxy	y 162	n 16	0.72	0.99	169.7 (68.4,421.1)
		y 63	n 1056			
<b>External data: Narcology Dispensary registration</b>						
Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	Control (index)	y 29	n 133	0.64	0.88	13.1 (6.7,25.5)
		y 16	n 962			
	Control proxy	y 28	n 138	0.65	0.87	12.9 (6.5,25.4)
		y 15	n 950			
	Case proxy	y 148	n 253	0.69	0.76	7.4 (5.2,10.5)
		y 65	n 821			

### 6.3.3 Agreement between questionnaire derived data and external data according to attributes of the index-proxy relationship

It is encouraging that the associations observed with external data when using questionnaire data from control proxies are very similar to those observed when using control data, and there is little indication of case/control bias in proxy reporting of these items. By repeating this previous analysis using subsets of the data defined by attributes of the index-proxy relationship, it is possible to investigate whether these associations are altered when the choice of proxy is further restricted to those who may be expected to more accurately report index behaviour.

#### *'Is the subject registered as disabled' and Social Security data*

Examination of the agreement between questionnaire data on whether the index is registered as disabled with external Social Security data on disability among subsets restricted by attributes of the index-proxy relationship is presented in Table 6.4. The very small number of subjects who are registered as disabled but reported not to be in the whole sample, and the even smaller number in the restricted subsets makes interpretation of these results difficult, since the precision of the findings is poor and point estimates are greatly affected by very minor changes in distribution of responses in the discordant cells of the contingency tables.

Overall it appears that restricting these data by attributes of the index-proxy relationship makes little difference to the results obtained in terms of sensitivity and specificity, and does not appear to affect the validity of proxy responses for this very objective question, other than weak evidence of a difference in the strength of association in control households where the proxy is the spouse (subset4) for both index and proxy respondents. This is in the opposite direction to that anticipated, whereby spouses as proxies are less likely to answer affirmatively where the index is registered disabled than the whole group, as indicated by lower sensitivity, and a correspondingly lower OR.

**Table 6.4** Association of questionnaire item 'Is he registered disabled' with Social Security registration by respondent and subset<sup>c</sup>

Respondent	Subset	y	n	Sensi- tivity	Speci- ficity	OR (95% CI)
Control (index)	All	y 49 n 3	22 1,066	0.94	0.98	791.4 (101.9,6145.0)
	Subset 1	y 45 n 3	21 980	0.94	0.98	700.0 (92.1,5319.0)
	Subset 2	y 41 n 3	20 903	0.93	0.98	617.1 (83.1,4580.0)
	Subset 3	y 46 n 3	20 975	0.94	0.98	747.5 (93.8,5956.0)
	Subset 4	y 30 n 3	20 931	0.91	0.98	465.5 (73.3,2957.0)
Control proxy	All	y 49 n 3	22 1,066	0.94	0.98	791.4 (101.9,6145.0)
	Subset 1	y 45 n 3	22 979	0.94	0.98	667.5 (90.7,4914.0)
	Subset 2	y 41 n 3	20 903	0.93	0.98	617.1 (83.1,4580.0)
	Subset 3	y 46 n 3	20 975	0.94	0.98	747.5 (93.8,5956.0)
	Subset 4	y 30 n 3	21 930	0.91	0.98	442.9 (71.6,2739.0)
Case proxy	All	y 310 n 8	64 920	0.97	0.93	557.0 (126.6,2452.0)
	Subset 1	y 273 n 6	54 791	0.98	0.94	666.5 (117.8,3772.0)
	Subset 2	y 270 n 5	53 705	0.98	0.93	718.3 (109.8,4699.0)
	Subset 3	y 292 n 8	58 808	0.97	0.93	508.5 (114.0,2267.0)
	Subset 4	y 202 n 4	41 537	0.98	0.93	661.4 (82.8,5282.0)

<sup>c</sup> Subset 1 = duration of index-proxy cohabitation at least 5 years; subset 2 = 'good' or 'extremely good' self-reported proxy knowledge of index; subset 3 = proxy-index contact at least daily; subset 4 = proxy was wife/girlfriend/partner (spouse).



***'Has the subject ever been in any kind of prison?' and Police data***

Examination of the agreement between questionnaire-derived data on whether the index has ever had a prison stay with external Police records of a prison stay in subsets restricted by attributes of the index-proxy relationship is presented in Table 6.5. Specificity is high and unchanged for all types of respondent in all subsets. Sensitivity is also almost unchanged, with the exception of case proxy data in subset 4. It appears that when considering only cases whose proxy is their wife, girlfriend or partner, those cases possessing a police record are less likely to be reported to have had one or more prison stay by their proxy. This tendency is supported by the 95% confidence interval for specificity, which is 0.54 - 0.74.

**Table 6.5** Association of questionnaire item *Has he ever spent time in any kind of prison reported by controls, control proxies and case proxies, and Police data regarding prison stays by subset<sup>d</sup>*

Respondent	Subset	y	n	sensitivity	specificity	OR (95% CI)
Control (index)	All	y 41 n 24	10 1,065	0.63	0.99	181.9 (59.5,556.3)
	Subset 1	y 33 n 23	7 986	0.59	0.99	202.1 (57.7,707.6)
	Subset 2	y 34 n 19	9 905	0.64	0.99	179.9 (53.9,601.1)
	Subset 3	y 41 n 23	8 972	0.64	0.99	216.6 (62.7,747.9)
	Subset 4	y 32 n 17	9 926	0.65	0.99	193.7 (56.3,666.4)
Control proxy	All	y 38 n 19	12 1,067	0.67	0.99	177.8 (58.9,537.3)
	Subset 1	y 32 n 18	8 988	0.64	0.99	219.6 (61.5,783.4)
	Subset 2	y 31 n 14	11 908	0.69	0.99	182.8 (54.3,615.4)
	Subset 3	y 37 n 19	11 973	0.66	0.99	172.3 (55.3,536.2)
	Subset 4	y 29 n 15	11 927	0.66	0.99	162.9 (50.5,525.8)
Case proxy	All	y 162 n 63	16 1,056	0.72	0.99	169.7 (68.4,421.1)
	Subset 1	y 123 n 43	14 942	0.74	0.99	192.5 (69.0,536.8)
	Subset 2	y 125 n 43	13 851	0.74	0.98	190.3 (66.0,548.9)
	Subset 3	y 142 n 56	13 951	0.72	0.99	185.5 (68.1,504.9)
	Subset 4	y 65 n 36	2 679	0.64	1.00	613.0 (64.1,5,865.0)

<sup>d</sup> Subset 1 = duration of index-proxy cohabitation at least 5 years; subset 2 = 'good' or 'extremely good' self-reported proxy knowledge of index; subset 3 = proxy-index contact at least daily; subset 4 = proxy was wife/girlfriend/partner (spouse).

*'Has the subject ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?', and Narcology Dispensary registration*

When examining the agreement between this questionnaire item and Narcology Dispensary registration among subsets restricted by attributes of the index-proxy relationship, a few notable differences emerge (Table 6.6). For all types of respondent, specificity estimates for this question are almost unchanged in any subset, indicating that the number of false positives is not reduced by restricting to certain households. Sensitivity estimates show very slight increases which in most occurrences are so small as to be disregarded, although there are some exceptions.

Among indexes (controls) for whom the proxy reports good or extremely good knowledge of the index (subset 2) and to a lesser extent, for indexes for whom the proxies are only spouses (subset 4) there is a lower proportion of false negatives. This is driven by a small change in absolute numbers, since the overall number of controls registered at the Narcology Dispensary is small. The precision of these estimates is therefore poor. The ORs for the overall association between question L36 reported by the index and Narcology Dispensary registration reflect these findings, whereby the magnitude of the association is larger when using subset 2 and especially subset 4, although the possibility that these observed differences have arisen by chance cannot be excluded. These results are broadly mirrored in the control proxy data, which reinforces the findings of the previous section, providing evidence of lack of bias in the use of a proxy versus the index. When using spouses (subset 4), however, the magnitude of the point estimate of the OR obtained when using proxy data is notably higher than when using index data, indicating that spouses are more likely to report the index having received professional help for an alcohol problem than the indexes on whom they are reporting.

This pattern of proxy reporting is broadly observed within case proxy data. Examining proxies who are spouse of the index, an increase in the validity of proxy responses is observed. An improvement in the association between questionnaire and external data is not detected when restricting to those households for which proxies report 'very good' or 'extremely good' knowledge of the index (subset 2), but there

is a weak suggestion that those who have cohabited with the index for at least 5 years (subset 1) provide slightly more valid responses than the unrestricted dataset.

**Table 6.6** Association of questionnaire item L36 (Has the subject ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?) and Narcology Dispensary registration by respondent and subset<sup>a</sup>

Respondent	Subset	y	n	sensitivity	specificity	OR (95% CI)
Control (index)	All	y 29 n 16	133 962	0.64	0.88	13.1 (6.7,25.5)
	Subset 1	y 25 n 13	127 884	0.66	0.87	13.4 (6.5,27.6)
	Subset 2	y 28 n 11	115 813	0.72	0.88	18.0 (8.4,38.8)
	Subset 3	y 28 n 15	121 880	0.65	0.88	13.6 (6.8,27.0)
	Subset 4	y 21 n 10	123 830	0.68	0.87	14.2 (6.3,31.8)
Control proxy	All	y 28 n 15	138 950	0.65	0.87	12.9 (6.5,25.4)
	Subset 1	y 24 n 13	133 874	0.65	0.87	12.1 (5.9,25.1)
	Subset 2	y 27 n 11	118 805	0.71	0.87	16.7 (7.8,36.1)
	Subset 3	y 27 n 14	129 865	0.66	0.87	12.9 (6.4,26.1)
	Subset 4	y 22 n 7	130 819	0.76	0.86	19.8 (8.0,49.2)
Case proxy	All	y 148 n 65	253 821	0.69	0.76	7.4 (5.2,10.5)
	Subset 1	y 135 n 51	221 712	0.73	0.76	8.5 (5.8,12.6)
	Subset 2	y 120 n 53	188 667	0.69	0.78	8.0 (5.4,11.9)
	Subset 3	y 124 n 54	220 758	0.70	0.78	7.9 (5.4,11.6)
	Subset 4	y 77 n 23	170 513	0.77	0.75	10.1 (5.9,17.3)

<sup>a</sup> Subset 1 = duration of index-proxy cohabitation at least 5 years; subset 2 = 'good' or 'extremely good' self-reported proxy knowledge of index; subset 3 = proxy-index contact at least daily; subset 4 = proxy was wife/girlfriend/partner (spouse).

### 6.3.4 Can narcology data be used to validate other alcohol-related questions?

In addition to the question on whether the subject has received professional help or advice for an alcohol problem in the past year (L36), the Izhevsk Family Study asked a large number of other questions relating to alcohol use, some of which were indicators of hazardous drinking, as described in Chapter 3 and Chapter 4. *A priori*, we would expect other reports of hazardous drinking to be related to Narcology Dispensary registration, which captures all those who have been registered at the Narcology Dispensary for help or advice for an alcohol problem. It is therefore of interest to explore whether questions providing reports of hazardous drinking behaviour are associated with Narcology Dispensary registration in cases and controls, an external indicator of hazardous drinking, in a similar way to question L36.

Of the large number of variables available relating to alcohol use, two questions emerged as particularly important indicators of hazardous drinking in mortality analyses carried out on the full dataset and on this basis have been selected for further exploration here. These are the questions relating to consumption of surrogates in the past year (L4), and whether the subject has been on zapoi in the past year (L25).

Not everyone who has an alcohol problem is expected to be registered at the Narcology Dispensary, and not everyone who is registered is expected to answer affirmatively to all questions about aspects of hazardous drinking behaviour. Specifically, the questions on surrogate use and zapoi ask about very different aspects of alcohol-related behaviour to question L36: they are not attempting to measure the same thing as the external data on Narcology Dispensary registration, which captures those who are registered for any alcohol problem rather than supplying behaviour-specific information. Therefore sensitivity and specificity are not appropriate measures to quantify the relationships between questionnaire data and external data. However, the strength of association (OR) is of interest (Table 6.7).

**Table 6.7** Association of questionnaire items 'Has he ever used surrogates in the past year?' and 'Has he been on zapoi in the past year?' with Narcology Dispensary registration by respondent.

Questionnaire item	Respondent	y	n	OR (95% CI)	
Has he drunk surrogates in the past year?	Control (index)	y	14	59	7.9 (3.9, 15.9)
		n	31	1036	
	Control proxy	y	14	78	6.4 (3.2, 12.9)
		n	28	1005	
	Case proxy	y	151	375	4.7 (3.3, 6.6)
		n	59	687	
Has he been on zapoi in the past year?	Control (index)	y	14	71	7.5 (3.6, 15.4)
		n	23	873	
	Control proxy	y	16	106	6.0 (3.0, 12.1)
		n	21	841	
	Case proxy	y	138	377	3.5 (2.5, 4.9)
		n	63	605	

For both questions examined here, the pattern observed when comparing the questionnaire item with Narcology Dispensary registration is close to expectations for control and control proxy data. A tendency is observed for proxies to slightly over-report the prevalence, on aggregate, of the index drinking surrogates in the past year and of having been on zapoi in the past year, compared with the index themselves. This is reflected in the lower OR obtained when using control proxy data. Overall however, the similarity of the results obtained when using control versus control proxy data, suggests that control proxies tend to report these behaviours accurately compared with the controls themselves. It appears, therefore, that Narcology Dispensary registration may also be used to validate proxy reports of other types of hazardous drinking among controls, by comparing associations with those obtained from index respondents.

For case proxy data, however, both ORs are substantially (although not statistically) weaker among case proxies than control proxies, suggesting that case proxies are less valid at reporting surrogate use and having been on zapoi with respect to Narcology Dispensary registration than control proxies. However, rather than these differences revealing a bias in the way case and control proxies report these questions, they may

be explained by different behavioural patterns among cases and controls with respect to alcohol consumption.

The differences between findings for cases and controls may be a reflection of the fact that alcohol consumption is closely related to mortality. Those controls who are registered at the Narcology Dispensary may be so for reasons relating to less extreme alcohol use than cases, or put another way, those subjects who are registered at the Narcology Dispensary because of extreme alcohol consumption behaviours are most likely to become cases. Correspondingly, reporting of these two behaviours will differ according to the extent of problem drinking, which is likely to be more extreme among cases than controls. Differences between case proxy and control proxy responses in this context cannot inform about case-control bias in the validity of proxy responses where the questions being examined are related to mortality.

#### **6.4 Discussion**

The results in this chapter indicate that there is an association between external data sources and self-reports of related questionnaire items where these are attempting to measure the same thing. This enables the use of these external data sources to validate proxy responses to these same questions using the whole analytic dataset, between case and control proxies in order to explore case-control bias in proxy reports of these questions and, finally, in subsets defined by the characteristics of the index-proxy relationship.

*Do proxies provide valid responses to questionnaire items with respect to external data sources?*

Based on the analyses presented here, it is possible to conclude that proxy respondents appear in general to provide valid responses to questions on receiving professional help or advice for alcohol problems, on registration of disability, and on prison stays, when these responses are examined with respect to appropriate external data records. These conclusions have been drawn by comparing the pattern of associations between control proxy reports and external data with those associations between index (control) reports and external data. An obvious limitation of this method is that control reports are not themselves assumed to accurately represent



true behaviour or events. However, given that in the absence of a gold standard, index reports are often assumed to be the best source of data, this method addresses the issue of whether proxies are as good as these preferred respondents in this context.

Since Social Security registration is concerned with receipt of money, it is unsurprising that there is a high correlation between reporting of disability registration and Social Security registration. However, the sensitivity observed for the question on prison stays as predictive of a Police record of the same is not particularly high. This may be attributable to the fact that this is an area which may be considered taboo and hence may be concealed by the index. It is also possible that very short stays in prison (the exact duration of which are not recorded in these data), which do result in an official Police record, are not considered to be a prison stay by respondents, but rather to be an encounter with the police. In this case, these two data sources may not be measuring exactly the same thing, so any measure of agreement is immediately compromised, regardless of data quality.

The low sensitivity obtained for control and control proxy respondents for the question 'Has the subject ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?' and Narcology Dispensary registration may reflect peculiarities in the representativeness of Narcology Dispensary registration, whereby a number of index subjects who have received such help or advice have done so from sources other than the narcology service. There may be cultural stigma associated with registration at the Narcology Dispensary, whereby respondents may not wish to admit to the subject having received professional help or advice for an alcohol problem. This would lead to a relative decrease in the prevalence of reporting of Narcology Dispensary registration. Alternatively, there may be issues with the comprehension of this question, whereby brief or unsolicited advice may not be considered or remembered when answering the questionnaire item, although these events will have resulted in Narcology Dispensary registration.

Overall, proxy respondents in the unrestricted dataset appear to provide valid responses to questionnaire items with respect to external data, when examined alongside self-reports of the same questions.

*Is there case-control bias in the reporting of these questionnaire items?*

Examination of results obtained using case proxy data is informative about whether there is case/control bias in proxy reporting of these questions with respect to external data sources. Although little statistical difference is observed between estimates of effect obtained using control proxy and case proxy data, some small differences in sensitivity and specificity are observed. This firstly reflects the slightly higher prevalence of each of these items among cases, but also suggests minor case-control bias in proxy reporting of these questions.

It is possible that some men may wish to conceal their status as disabled from their proxies for reasons of financial control within the household, embarrassment or other reasons. This would apply to both types of index. However, the severity of disability, where it arises, could plausibly be greater among cases. The consequences of this for measures of validity examined here are twofold: where the proxy is guessing the response to the question on disability registration rather than being in possession of the facts, the observed higher sensitivity in cases could plausibly arise because case indexes are less able to conceal their disabilities than controls, or alternatively, cases appear to proxies to have a disability that would lead to registration, even where this is not the case.

Bias in prison stay items may be explained in a similar way. The nature of offences committed by controls may be more likely to be minor offences than those committed by cases. Such offences would result in having a Police record of having spent time in prison, but this may have been of such brevity that the control/control proxy would not consider it a prison 'stay'. This would lead to the higher observed sensitivity among cases. Additionally, shorter prison stays of a day or less would be more easily concealed than longer stays by indexes who wished to do so, and these indexes would plausibly be more likely to be controls.

Finally, the clear difference in the association between case proxy and control/control proxy reports of having had help or advice for an alcohol problem and Narcology Dispensary registration may be explained in terms of the last results presented in the previous section: this question addresses behaviour which is related to mortality. Case proxies have higher levels of hazardous drinking behaviours, and

hence there are simply more cases proxies who answer in the affirmative to the questionnaire item, inevitably leading to higher sensitivity and lower specificity.

In summary, there are small but observable differences in the observed associations between case and control proxy questionnaire items and external data sources. Generally, these can be attributed to differences in behaviours and characteristics of indexes, rather than a case/control bias in proxies responses to these questions.

*Is validity affected by the choice of proxy respondent?*

Examination of these associations among defined by characteristics of the index-proxy relationship revealed whether choice of proxy has any impact on the validity of proxy responses, with respect to external data.

Apart from a few exceptions, restriction of the analyses to subsets defined by attributes of the index-proxy relationship does not substantially alter the validity of control proxies, when compared with the whole sample, although there is – inevitably – a tendency for slightly increased sensitivity in these nested subsets. There is some suggestion that subset 4 consists of proxy respondents who provide slightly more, although sometimes less, valid responses to the questions examined here. It is intuitive that proxies who are the wife, girlfriend or partner of the index would have good knowledge of the index's behaviour and therefore be in a strong position to provide valid responses. This is in line with the findings of the literature review in Chapter 1, which established that there is a general consensus in the literature that spouses make the best proxies. Apart from some weak evidence that proxies who report 'very good' or 'extremely good' knowledge of the index (subset 2) also provide slightly more valid responses, any positive effect of restricting by other index-proxy attributes is rather less convincing, and appears to depend on the specific question being examined and the type of index (case or control).

It is possible to hypothesise why proxies in subset 4 appear to provide more or less valid responses on a question by question basis. Beginning with items related to disability registration, it is surprising that spouses do not appear to be better informed of this official status than other types of proxy. However, examination of the raw data reveals that the number of discordant pairs is almost unchanged in this group compared with the whole sample, and the changes in sensitivity and the OR obtained

are largely driven by substantial changes in the denominators of these measures relative to the numerators: thus this observation is to some extent artefactual. It is notable that in subset 4 (spouses only) for cases, the index is less likely to be reported to have been in prison. This may be because spouses are somehow more badly informed than other proxies about these events. However, far more likely is that this is a reflection of the nature of offences committed by those who have spouses. Cases who have a spouse may be likely to commit more minor offences than men who do not have spouses, leading, as discussed above, to the existence of a Police record on the basis of an event that does not lead to an affirmative questionnaire response by the proxy. Finally, consideration of the agreement between the question 'Has the subject ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?' and Narcology Dispensary registration reveals that there is improvement in proxy validity, indicated by higher sensitivity and a correspondingly higher OR, when only using spouses (subset 4) in both case and control households. This supports an argument for using spouses as proxies, in preference to even the index themselves, as the most valid, respondent type.

It is interesting that in the examination of subsets, the results obtained when using control proxy responses are very similar to those obtained when using self-reported control data. This finding suggests that the index-proxy relationship attributes that are associated with more valid proxy responses also affect the type of index being examined within these subsets, so that they themselves also provide more valid data. This is an important finding: it suggests that differences observed are as much a reflection of the types of men who have a spouse, as it is a reflection of the ability of these spouses to report on the index; it is logical to assume that the proxy available for interview is not random, but is a function of characteristics of the index.

Since the subsets being examined are all nested within the larger sample, it is plausible that variations observed in the apparent validity of proxy responses are attributable to comparing non-independent samples. Ideally, each subset could be compared with its inverse, a sample comprising those not in that subset. However, the small numbers of observations in some cells preclude this approach, as the findings would not be sufficiently robust to be informative. Subset 4 in particular (spouses only) for which the most convincing evidence of a difference in reporting is

observed is substantially smaller in size than the other subsets examined. The bigger difference observed in the size of the effects when compared to other, larger, subsets could be due to the distribution, whereby real but small differences in proxy validity have greater weighting than similar differences in larger nested subsets when compared to the whole sample. This could account for the changes observed in associations when using proxy respondents who had been cohabiting with the index for at least 5 years (subset 1) and those who reported 'very good' or 'extremely good' knowledge of the index (subset 2) for the items related to Narcology Dispensary registration. Whilst avoiding over-interpretation of these small improvements, it is worth noting that they are not unexpected. The proxy respondents included in these two subsets could plausibly be expected to be better able to report index behaviours than other proxies, and with more statistical power, the findings could emerge to be more convincing.

An examination of the sensitivity and specificity obtained for respondents *not* in subset 4 for question L36 and Narcology Dispensary registration helps clarify this point. The sensitivity for case proxy, control proxy and control respondents not in subset 4 are 0.63, 0.43 and 0.57 respectively, and the specificities are 0.79, 0.94, 0.93 respectively. It is notable that for all categories, the trends - albeit small - are opposite for those not in subset 4 to those in subset 4. In particular, the sensitivity for control proxies is lower for those not in subset 4 than for those in subset 4, and relative to the whole sample. This supports the finding that those in subset 4 (spouses) may provide more valid responses.

### *Concluding comments*

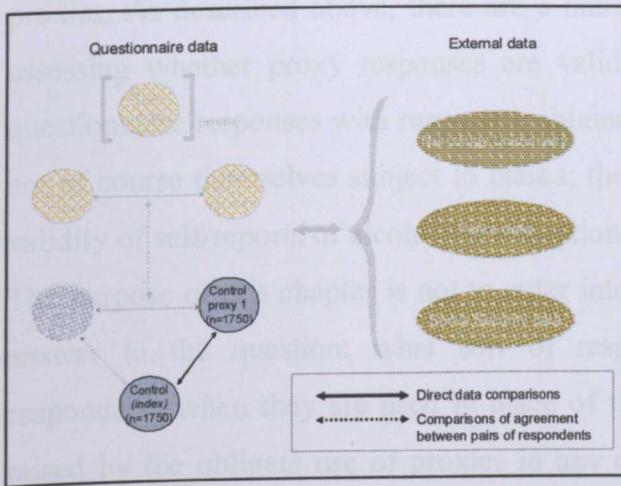
In conclusion, the results presented in this chapter provide evidence that proxies provide valid responses to a range of questions with respect to external data sources measuring the same underlying behaviours and events.

There is some weak evidence of case control bias in the way that proxies report the question examined in this chapter, but this can be explained to some extent in terms of inherent behavioural differences between indexes who are cases and those who are controls, rather than differences in the validity in the proxy reports of these questions.

Most strikingly, in line with the consensus in the extant literature, there is evidence that spouses (subset 4) provide more valid responses. These findings are explored further using different analytic approaches and a wider range of questions in the following chapters.

# Chapter 7 Agreement between proxy and index respondents

What sort of response can be obtained when using proxy respondents in place of the index themselves? The use of proxy respondents is sometimes inevitable when the index themselves is not available. Some of the consequent methodological difficulties introduced when using proxy respondents have been discussed earlier in



this thesis. In this chapter we turn to using the index as a reference against which to evaluate the validity of proxy responses. As described in the previous chapter and Chapter 1, a number of studies have attempted to quantitatively address the issue of whether proxy respondents are valid substitutes for an index subject,

but no definitive 'answer' has been achieved to date. In this chapter, the unique dataset obtained from the Izhevsk Family Study which comprises a complete set of index and proxy reports for a large number of controls will be used to empirically investigate the question of what sort of response can be obtained relative to the index when using a proxy, sometimes the only available choice, and how this is affected by characteristics of the index-proxy relationship of the formal index-proxy relationship. Where discrepancies in reporting between index and proxy are identified, the directionality of misclassification by proxies is evaluated.

## 7.1 Summary of chapter contents

This chapter assesses the agreement of proxy reports with the index report among controls from the Izhevsk Family Study, focusing on questions about alcohol use, and also considering questions on tobacco use, socioeconomic factors and three

health questions. By repeating the analyses on restricted groups of respondents, defined by attributes of the index-proxy relationship, this chapter then explores whether these attributes affect agreement of proxy responses. Finally, an evaluation of direction of misclassification in the proxy relative to the index response is conducted.

## **7.2 Background**

There are instances in observational research in which there is no option but to use proxies. As described above, there are a number of approaches to the challenge of assessing whether proxy responses are valid. One of these is to compare proxy questionnaire responses with responses obtained from the index themselves. Indexes are of course themselves subject to biases; there is ongoing extensive debate on the validity of self-reports of alcohol consumption and other behaviours<sup>(49-51,53,54,56,57,137)</sup>. The purpose of this chapter is not to enter into that debate, but rather, to provide an answer to the question: what sort of response can be obtained from proxy respondents when they are used in place of the index? This is the central question raised by the obligate use of proxies in any case-control study where the case has died or is unable to respond for whatever reason.

It is well-established that indexes themselves are a fallible source of data, especially for alcohol-related questions<sup>(50)</sup>. Index responses may be influenced by a wide range of factors including forgetfulness, embarrassment, shame, or at the other end of the spectrum a desire to enhance their image or gain access to resources by painting a biased picture of their behaviour or situation<sup>(49)</sup>. These factors will vary across members of a study population, leading to inconsistency in terms of the relative under/over reporting by the index compared with proxy reports.

Having previously highlighted the importance of alcohol use as an exposure in the Russian mortality crisis and for the Izhevsk Family Study, in this chapter, the focus will continue to be on alcohol-related questionnaire variables. There is a literature on the validity of proxy responses with respect to alcohol use within which it is generally suggested that proxies may overestimate alcohol consumption relative to the index (see Chapter 1). Additionally, a range of questions relating to tobacco use, health and socioeconomic factors will be again considered.



As in the previous chapter, the analyses carried out will be repeated on a reduced portion of the dataset, on samples defined by characteristics of the index-proxy relationship and by the formal index-proxy relationship. This approach is being used to triangulate and extend the findings from the previous chapter regarding whether such attributes of the index-proxy relationship affect the validity of proxy responses.

### **7.3 Methods**

The methods used to evaluate the quality of proxy responses with respect to index data are described in more detail in Chapter 5

In this chapter, Cohen's kappa coefficient, weighted or unweighted as appropriate, is used to initially assess the level of agreement beyond that expected by chance alone between index and proxy reports of questions relating to alcohol use, tobacco use and a selection of other exposures among control households for non-missing data. All non-nested questions (i.e. not asked based on responses to previous questions) were examined. The strengths and weaknesses of Cohen's kappa coefficient are discussed in Chapter 5. The distribution of responses by informant type was obtained using simple cross-tabulations in order to aid interpretation of kappa coefficients. Analyses were repeated restricting to subsets defined by attributes of the index-proxy relationship as described in Chapter 4<sup>f</sup>. Agreement was interpreted in accordance with the scheme developed by Landis and Koch<sup>(67)</sup>: <0, poor; 0.00–0.20, slight; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; >0.8, almost perfect.

One of the issues of particular interest in the context of the Izhevsk study was how far control proxies over- or under-estimated exposures relative to the control. McNemar's test was used to evaluate the directionality of discordance between observers. This chi-squared statistic was based on the proportion of discordant pairs, whereby all discordant pairs of observations were grouped according to the direction of their disagreement (proxy over- or under- reporting relative to the control). The

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<sup>f</sup> Subset 1 = duration of index-proxy cohabitation at least 5 years; subset 2 = 'good' or 'extremely good' self-reported proxy knowledge of index; subset 3 = proxy-index contact at least daily; subset 4 = proxy was wife/girlfriend/partner (spouse).

magnitude of the chi-squared statistic and its p value obtained on 1 degree of freedom were used to interpret whether or not the directionality of disagreement could have arisen due to chance.

In order to formally evaluate the relative strength of index-proxy agreement in the subsets, log-linear models after Agresti of the difference in agreement between classes of rater pairs were fit to the data<sup>(128)</sup>, comparing those index-proxy pairs within each subset to all other respondents. The magnitude and significance of the derived parameter representing the difference in agreement between index-proxy pairs included versus excluded from any particular subset,  $\tau$ , was then examined for each question (e.g. pairs included in subset 1 compared with pairs not included in subset 1). By then obtaining z scores for  $\tau$  ( $\tau$ /standard error), the normalised  $\tau$  coefficients were displayed on a quantile-quantile plot in order to visually examine which of the  $\tau$ /standard error values lay outside the range expected under the assumption of a normal distribution.

In order to assess whether there was a tendency for directionality in the difference in agreement for any particular subset, a sign test to assess the proportion of  $\tau$  coefficients which were above, versus below, the null value of 0 (representing no difference between groups) was carried out over all questions. Since the sign test is carried out on a number of  $\tau$  coefficients obtained from the same individuals over a selection of questions, the coefficients are not independent, invalidating the sign test. This measure is, however, useful as an indication of presence or absence of a tendency for one set of pairs of raters to exhibit greater agreement than the other.

## **7.4 Results**

As described in Chapter 4, for 90% of control households in which a proxy interview was obtained, a control interview was also successfully obtained. This resulted in 1580 pairs of index-proxy interviews. After exclusions carried out to ensure quality of interviews obtained, 1140 index-proxy interview pairs were suitable for analysis.

Table 7.1 displays Cohen's kappa coefficients for index-proxy pairs for each of 44 questions, for the unrestricted sample and for those pairs included in each of the subsets examined. Results are ordered according to the kappa coefficient obtained for

the unrestricted sample of 1140 households in which an eligible control and control proxy interview were obtained. In the table, the threshold between each interpretative category as prescribed by Landis and Koch<sup>(67)</sup> is indicated by a solid line. Results are described below by subject area, beginning with questions related to alcohol use, and followed by questions related to tobacco use, socioeconomic factors and health questions.

#### 7.4.1 Index-proxy agreement for alcohol-related variables

When examining the unrestricted sample, none of the 30 questions displayed the highest level of agreement, corresponding to kappa coefficients in the 'almost perfect' category ( $>0.8$ ), nor did any display agreement in the 'slight' or 'poor' categories ( $\text{kappa} < 0.2$ ). The majority of questions fell in the 'moderate' range ( $0.4 < \text{kappa} < 0.6$ ), and the rest were distributed between 'substantial' and 'fair' agreement. Some specific comments follow.

Table 7.1 shows that the highest index-proxy agreement for alcohol use questions was observed for 5 items whose kappa coefficients were in the range 0.6-0.8, corresponding to a 'substantial' level of agreement. These questionnaire items included the queries about the days on which beer, spirits and other alcoholic substances are usually drunk (rather than quantity consumed), and two items relating to help for alcohol-related problems, 'Has he ever had help or advice from a doctor, narcologist, social worker or other health professional for an alcohol problem?', and 'Has he ever been taken to a sobering up centre?'. Of particular interest is the binary variable describing whether the index ever drinks surrogates, an extreme drinking behaviour, which was derived from the question about frequency of drinking surrogates. This question was at the lower end of the 'substantial' agreement range ( $\text{kappa} = 0.62$ , 95% CI 0.53 - 0.71).

The majority of questions relating to alcohol use showed kappa coefficients for agreement beyond that expected by chance alone in the 'moderate' agreement range 0.4-0.6, indicating that in general, proxies can provide reasonably accurate reports of alcohol use relative to the index. Questions on the maximum and the usual quantity of beer, wine and spirits consumed fell in this range, although the coefficients for agreement on the questions relating to spirits were at the lower end of this range

(kappa = 0.49, 0.46 respectively), whilst those for beer and wine were at the upper end (kappa = 0.54, 0.58). Conversely, questions asking on which day any of these drinks are usually consumed all fell at the lower end of this scale (kappa  $\leq$  0.49). The question about whether the man had had one or more episodes of *zapo*<sup>8</sup> in the past year displayed 'moderate' agreement (kappa = 0.57). A number of other questions about behaviours indicating hazardous drinking, rather than about consumption itself, also fell in the 'moderate' range. These included 'Has he been arrested because of being drunk during the past year', 'How often does he fail to fulfil his work obligations due to drinking alcohol?', 'How often does he have a hangover?', 'Does he ever drink alcohol before noon?', 'How often does he become excessively drunk?' and 'Does he ever drink alone?' Finally, the questions on usual frequency of consumption of surrogates and wine showed 'moderate' agreement.

Seven of the 30 questions examined showed the lowest agreement, kappa = 0.2-0.4, corresponding to 'fair' agreement. Questions on whether the man drinks more, less or about the same now compared to one year or one month in the past exhibited the lowest of the questions examined. Three of the questions in this section referred to behaviours which would be likely to occur outside the home and are therefore not easily observable by proxies. These were 'Does he usually drink alcohol at home or in other places?', 'Does he ever drink spirits together with either beer or wine at the same sitting?' and 'Does he ever drink large quantities of spirits without also eating some food?' Other questions showing 'fair' agreement are those asking about frequency of going to bed clothed due to being drunk, although it should be noted that the number of controls responding to this question in the affirmative were again low, compromising the robustness of the estimate, and the charged question 'How often does he fail to fulfil his family or personal obligations due to drinking alcohol?'.

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<sup>8</sup> *Zapo*: a period of continuous drunkenness lasting several days.

**Table 7.1** *Cohen's kappa coefficients for agreement between control index and control proxy for alcohol, tobacco use, socioeconomic factors and health questions by subset<sup>h</sup>*

<b>Q</b>	<b>Question text</b>	<b>Weighted</b>	<b>All (n=1140)</b>	<b>Subset 1 (n=1049)</b>	<b>Subset 2 (n=967)</b>	<b>Subset 3 (n=1044)</b>	<b>Subset 4 (n=984)</b>
J8	Is he registered disabled?	N	0.99	0.99	0.98	0.98	0.99
M1	Is he a current smoker?	N	0.95	0.95	0.96	0.95	0.95
E15	What is his marital status?	Y	0.96	0.95	0.95	0.96	0.95
F3	Is he in regular paid employment?	N	0.88	0.89	0.89	0.88	0.88
F1	What is his level of education?	Y	0.87	0.87	0.88	0.89	0.88
M2	How many years ago did he stop smoking regularly?	Y	0.85	0.87	0.87	0.86	0.88
C14	Does his household own a car?	N	0.85	0.84	0.83	0.85	0.84
L36	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	N	0.79	0.79	0.79	0.78	0.78
M3	What does he smoke most often?	Y	0.79	0.77	0.81	0.80	0.78
M6	Have his parents ever smoked?	N	0.75	0.75	0.76	0.75	0.74
L38	Has he ever been taken to a sobering up centre?	Y	0.72	0.72	0.72	0.72	0.73
L1	How often is beer usually drunk?	Y	0.65	0.65	0.65	0.65	0.66
L3	How often are spirits usually drunk?	Y	0.63	0.63	0.63	0.63	0.65
K1	Has he had any broken bones in the past year?	N	0.64	0.62	0.68	0.66	0.65

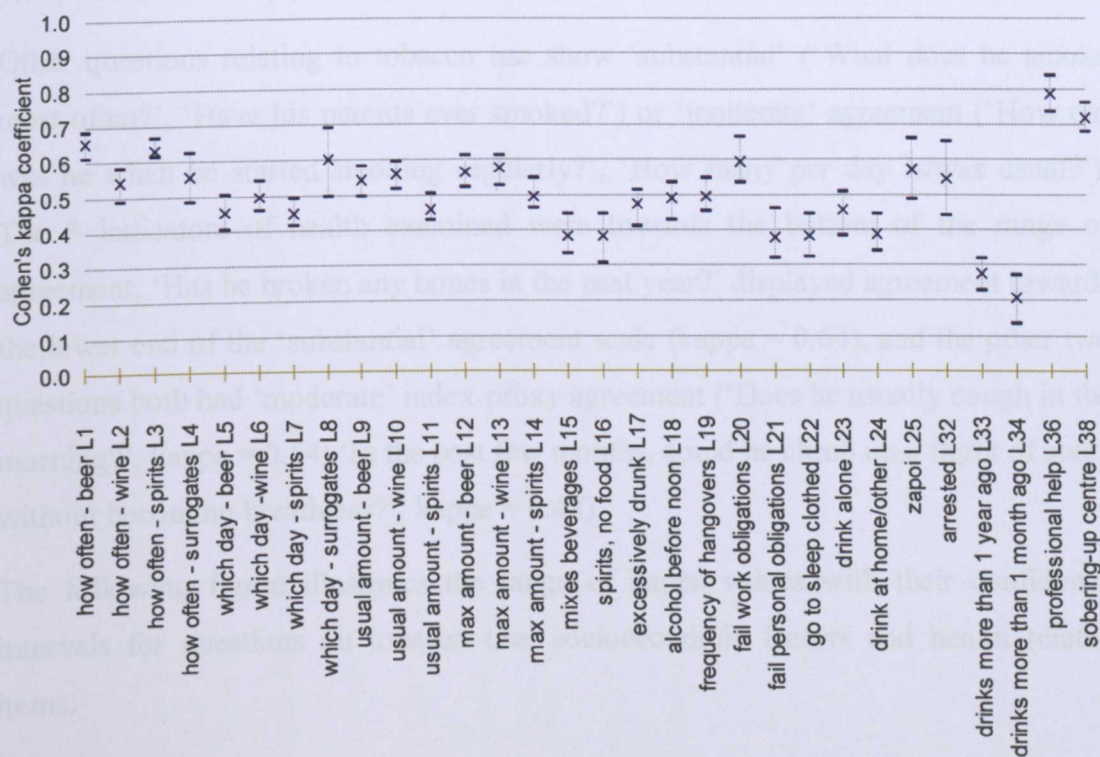
<sup>h</sup> Subset 1 = duration of index-proxy cohabitation at least 5 years; subset 2 = 'good' or 'extremely good' self-reported proxy knowledge of index; subset 3 = proxy-index contact at least daily; subset 4 = proxy was wife/girlfriend/partner (spouse).

Q	Question text	Weighted	All (n= 1140)	Subset 1 (n= 1049)	Subset 2 (n= 967)	Subset 3 (n= 1044)	Subset 4 (n= 984)
L8	On which day are other alcoholic substances usually drunk?	Y	0.60	0.60	0.59	0.61	0.60
L20	How often does he fail to fulfil his work obligations due to drinking alcohol?	N	0.59	0.59	0.62	0.59	0.59
L13	What is the maximum quantity of wine ever drunk on one occasion?	Y	0.58	0.57	0.58	0.58	0.61
L25	Has he had one or more episodes of zapoi in the past year?	N	0.57	0.55	0.57	0.58	0.55
L10	How much wine is usually drunk on one occasion?	Y	0.56	0.56	0.57	0.56	0.59
L12	What is the maximum quantity of beer ever drunk on one occasion?	Y	0.56	0.55	0.55	0.56	0.57
L4	How often are other alcoholic substances drunk?	Y	0.55	0.55	0.58	0.56	0.54
L32	Has he been arrested because of being drunk during the past year?	Y	0.55	0.54	0.58	0.53	0.54
L2	How often is wine usually drunk?	Y	0.54	0.54	0.55	0.55	0.56
M5	How old was he when he started smoking regularly?	Y	0.54	0.53	0.54	0.54	0.56
L9	How much beer is usually drunk on one occasion?	Y	0.54	0.53	0.53	0.54	0.55
K2	Does he usually cough in the morning?	Y	0.51	0.51	0.53	0.51	0.52
L18	Does he ever drink alcohol before noon?	Y	0.49	0.50	0.52	0.50	0.52
L14	What are the maximum quantity of spirits ever drunk on one occasion?	Y	0.49	0.49	0.49	0.49	0.50
L6	On which day is wine usually drunk?	Y	0.49	0.49	0.50	0.49	0.51
L19	How often does he have a hangover?	Y	0.50	0.49	0.50	0.50	0.51
M4	When he smoked, how many per day was usual?	Y	0.49	0.49	0.48	0.49	0.51

<b>Q</b>	<b>Question text</b>	<b>Weighted</b>	<b>All (n= 1140)</b>	<b>Subset 1 (n= 1049)</b>	<b>Subset 2 (n= 967)</b>	<b>Subset 3 (n= 1044)</b>	<b>Subset 4 (n= 984)</b>
L17	How often does he become excessively drunk?	Y	0.47	0.47	0.48	0.47	0.48
K3	In the past few months, could he climb up a flight up of stairs without becoming breathless?	Y	0.48	0.46	0.45	0.47	0.45
L23	Does he ever drink alone?	N	0.46	0.45	0.46	0.44	0.47
L11	What quantity of spirits is usually drunk on one occasion?	Y	0.46	0.45	0.46	0.45	0.46
L7	On which day are spirits usually drunk?	Y	0.45	0.44	0.45	0.45	0.46
L5	On which day is beer usually drunk?	Y	0.45	0.44	0.44	0.45	0.46
L24	Does he usually drink alcohol at home or in other places?	Y	0.39	0.39	0.39	0.39	0.40
L16	Does he ever drink large quantities of spirits without also eating some food?	Y	0.38	0.38	0.37	0.39	0.38
L21	How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	Y	0.38	0.37	0.40	0.37	0.39
L15	Does he ever drink spirits together with either beer or wine at the same sitting?	N	0.38	0.37	0.40	0.38	0.40
L22	Does he ever go to sleep at night without taking his clothes off because of being drunk?	N	0.38	0.37	0.39	0.38	0.38
L33	Does he currently drink more, less or about the same as one year ago?	Y	0.27	0.29	0.28	0.27	0.29
L34	Does he currently drink more, less or the same as one month ago?	Y	0.21	0.22	0.21	0.22	0.21

The following figure illustrates the range of kappa values with their confidence intervals for questions on alcohol (Figure 7.1).

Figure 7.1 Kappa for whole sample and confidence intervals: alcohol questions



#### 7.4.2 Index-proxy agreement for tobacco use and other exposure variables

As expected, due to fact that these items are asking about potentially less sensitive behaviours than alcohol-related questions which are therefore less likely to be concealed, index-proxy agreement for the 14 questions examined in this analysis show high agreement, with the majority displaying kappa coefficients of 0.85 and above ('almost perfect' agreement), and the rest displaying 'substantial' or 'moderate' agreement. The question showing highest agreement, 'Is he registered disabled', has a kappa value of 0.99. The aggregate distribution for this question is identical for controls and their proxies, and a cross tabulation reveals that there is only 1 misclassification by each respondent relative to the other. The kappa coefficients for the four questions on aspects of socioeconomic status are also among the highest, indicating proxy validity relative to the index: 'What is his marital status' (kappa = 0.96), 'Is he in regular paid employment' (kappa = 0.88), 'What is his level of education' (kappa = 0.87) and 'Does his household own a car' (kappa = 0.85). Also displaying 'almost perfect' agreement are two questions relating to the

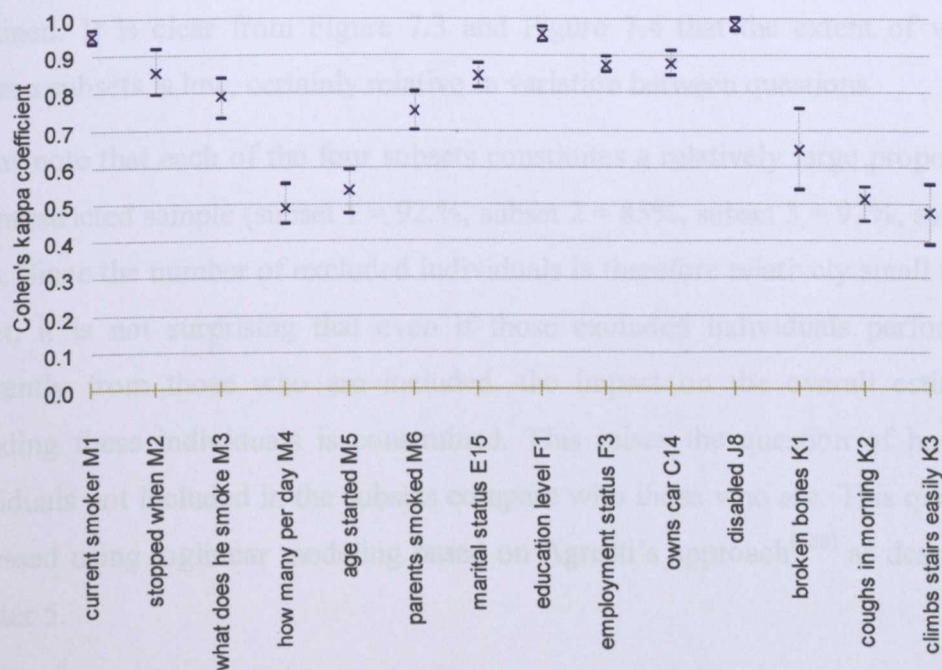


most easily observable aspects of tobacco use, 'Is he a current smoker?' (kappa = 0.95) and 'How many years ago did he stop smoking?' (kappa = 0.85).

Other questions relating to tobacco use show 'substantial' ('What does he smoke most often?', 'Have his parents ever smoked?') or 'moderate' agreement ('How old was he when he started smoking regularly?', 'How many per day is/was usual?'). The 3 indicators of health examined were towards the bottom of the range of agreement. 'Has he broken any bones in the past year?' displayed agreement towards the lower end of the 'substantial' agreement scale (kappa = 0.64), and the other two questions both had 'moderate' index-proxy agreement ('Does he usually cough in the morning?', kappa = 0.54; 'In the past few months, could he climb up a flight of stairs without becoming breathless?', kappa = 0.48).

The following figure illustrates the range of kappa values with their confidence intervals for questions on tobacco use, socioeconomic factors and health related items.

Figure 7.2 Kappa for whole sample and confidence intervals: tobacco use, socioeconomic factors, and health related questions



### 7.4.3 Restriction to subsets

The kappa coefficients obtained for each question when the data are restricted to subsets defined by attributes of the index-proxy relationship are presented in Table 7.1. Examination of these kappa coefficients reveals that each question elicits similar control-proxy agreement regardless of the characteristics used to define the subset. Whilst usually small, certain effects on the index-proxy concordance are observable.

After exclusion of those proxies who had not cohabited with the index for at least 5 years, the pattern of index-proxy agreement was very similar to that observed in the whole dataset. Subset 2, comprising only those index-proxy pairs for whom the proxy self-reported 'very good' or 'extremely good' knowledge of the index displayed better performance than the unrestricted sample for 2 questions: agreement was slightly better for question K1, 'Has he broken any bones in the past year?' and for L32, 'Has he been arrested because of being drunk during the past year'. Subset 3, comprising proxies who report daily contact with the control, and subset 4,

comprising spouses only, both perform very similarly to the unrestricted sample of proxies, with almost no evidence of an improvement or deterioration in concordance.

Although formal comparisons of kappa values cannot be undertaken, the following two figures show the kappa coefficients for each question for each of the subsets examined. It is clear from Figure 7.3 and Figure 7.4 that the extent of variation between subsets is low, certainly relative to variation between questions.

It is of note that each of the four subsets constitutes a relatively large proportion of the unrestricted sample (subset 1 = 92.%, subset 2 = 85%, subset 3 = 92%, subset 4 = 85%). Since the number of excluded individuals is therefore relatively small for each subset, it is not surprising that even if those excluded individuals perform very differently from those who are included, the impact on the overall estimate of excluding these individuals is constrained. This raises the question of how those individuals not included in the subsets compare with those who are. This question is addressed using loglinear modeling based on Agresti's approach<sup>(128)</sup> as described in Chapter 5.

Figure 7.3 Cohen's kappa coefficient for the unrestricted sample and four subsets, alcohol questions

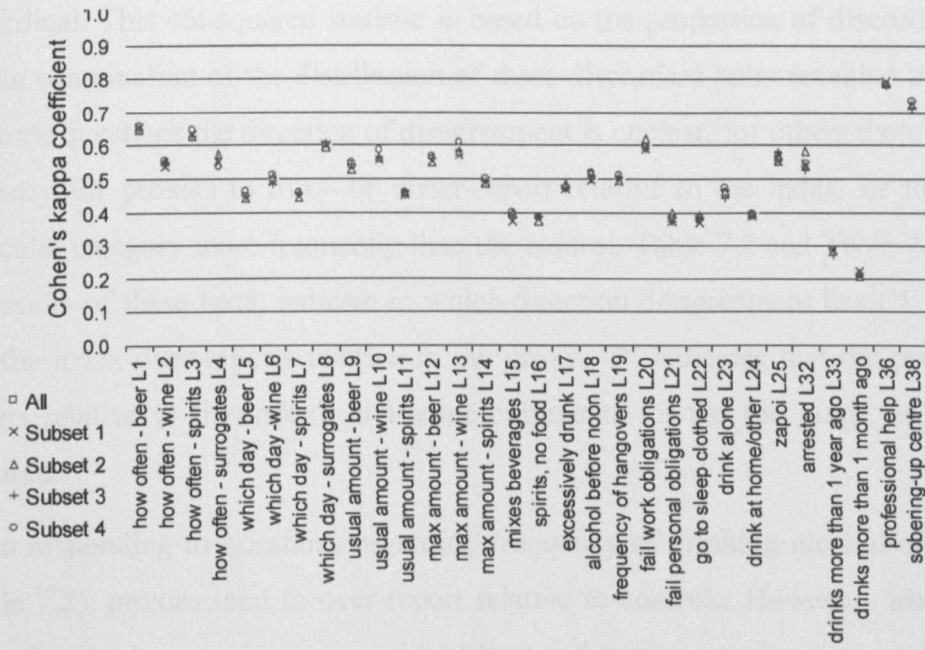
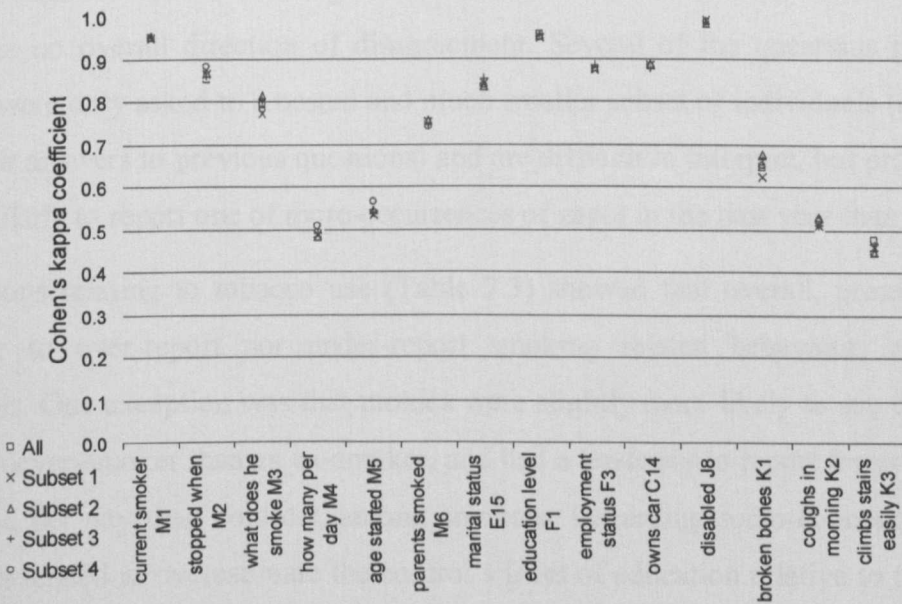


Figure 7.4 Cohen's kappa coefficient for the unrestricted sample and four subsets, other questions



#### 7.4.4 Do proxies over or underestimate relative to controls?

In order to evaluate the direction of disagreement, where it occurs, McNemar's test for homogeneity of discordant pairs was calculated for questions where categories are ordinal. This chi-squared statistic is based on the proportion of discordant pairs, and an examination of the distribution of these discordant pairs revealed that whilst for some questions the direction of disagreement is unclear, for others there is a clear tendency for proxies to over- or under-report relative to the index, or to report a particular category more frequently than the control. Table 7.2 and Table 7.3 display the results of these tests, indicate in which direction disagreement lies ('I' indicates that the index over-reports relative to the proxy, 'P' indicates that the proxy over-reports relative to the index), and some comments for the full range of questions explored.

When responding to questions regarding frequency of drinking alcohol of all types (Table 7.2), proxies tend to over-report relative to controls. However, when asking about the usual or maximum quantity of beer and spirits consumed on one occasion, proxies tend to report consumption of smaller quantities relative to the control. For almost all the 'indicator' questions about behaviours related to hazardous drinking, proxies are more likely than controls to report occurrence, or to report more frequent occurrence of these behaviours. Exceptions are 'How often does he fail to fulfil his work obligations due to drinking alcohol?' and 'Does he ever drink alone?' for which there is no overall direction of disagreement. Several of the questions relating to zaponi were only asked to a nested and much smaller subset of individuals (dependent on their answers to previous questions) and are difficult to interpret, but proxies were more likely to report one or more occurrences of zaponi in the past year than controls.

Questions relating to tobacco use (Table 7.3) showed that overall, proxies tended neither to over-report nor under-report smoking related behaviour, relative to controls. One exception was that proxies were slightly more likely to say the control was a never-smoker than an ex-smoker, and had a tendency to report fewer cigarettes smoked per day than controls, among smokers. Regarding socio-economic factors, proxies tended to overestimate the control's level of education relative to the control themselves, and were less likely to report that the household had a car. Other socio-economic factors showed little directionality in pairwise disagreement. Proxies

appeared to report that the index had poorer health than the index themselves: proxies were more likely than controls to report coughing in the morning, and overestimate how difficult the control finds it to climb a flight of stairs without becoming breathless.

**Table 7.2** *Number of discordant and concordant index-proxy responses for alcohol questions*

Q	Question text	Proxy or index over-report? <sup>i</sup>	Discordant pairs proxy> control (n)	Concordant pairs control> proxy (n)	McNemar's chi squared	p value (1df)	Comment
L1	How often is beer usually drunk?	P	263	212	5.48	p<0.05	proxy tends to report more frequent drinking of beer
L2	How often is wine usually drunk?	P	194	123	15.90	p<0.001	proxy tends to report more frequent drinking of wine
L3	How often are spirits usually drunk?	P	222	214	0.15	p>=0.05	
L4	How often are other alcoholic substances drunk?	P	61	25	15.07	p<0.001	proxy tends to report more frequent drinking of surrogates
L9	How much beer is usually drunk on one occasion?	I	128	170	5.92	p<0.05	proxy tends to report smaller quantities
L10	How much wine is usually drunk on one occasion?	I	143	149	0.12	p>=0.05	
L11	What quantity of spirits is usually drunk on one occasion?	I	219	277	6.78	p<0.05	proxy tends to report smaller quantities
L12	What is the maximum quantity of beer ever drunk on one occasion?	I	139	207	13.36	p<0.001	proxy tends to report smaller quantities
L13	What is the maximum quantity of wine ever drunk on one occasion?	I	129	155	2.38	p>=0.05	
L14	What is the maximum quantity of spirits ever drunk on one occasion?	I	193	305	25.19	p<0.001	proxy tends to report smaller quantities
L17	How often does he become excessively drunk?	P	256	135	37.45	p<0.001	proxy more likely to answer in the affirmative

<sup>i</sup> 'P' indicates that proxies tend to over-report relative to indexes. 'I' indicates that indexes tend to over-report relative to proxies

Q	Question text	Proxy or index over-report?	Discordant pairs		Concordant pairs (n)	McNemar's chi squared	p value (1df)	Comment
			proxy > control (n)	control > proxy (n)				
L18	Does he ever drink alcohol before noon?	P	122	92	750	4.21	p<0.05	proxy more likely to answer in the affirmative
L19	How often does he have a hangover?	P	207	160	575	6.02	p<0.05	proxy tends to report more frequent hangovers
L20	How often does he fail to fulfil his work obligations due to drinking alcohol? How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	I	43	62	865	3.44	p>=0.05	
L21	Does he ever go to sleep at night without taking his clothes off because of being drunk?	P	172	82	690	31.89	p<0.001	proxy tends to report more frequent occurrence
L22	Does he ever drink alone?	P	174	48	750	71.51	p<0.001	proxy tends to report more frequent occurrence
L23	Has he had one or more episodes of zapoi in the past year?	P	161	145	655	0.84	p>=0.05	
L25	During his most recent period of heavy drinking, what was the maximum quantity of beer drunk?	P	65	22	884	21.25	p<0.001	proxy more likely to answer in the affirmative
L28	During his most recent period of heavy drinking, what was the maximum quantity of wine drunk?	P	2	1	7	0.33	p>=0.05	
L29	During his most recent period of heavy drinking, what was the maximum quantity of spirits drunk?	P	3	2	6	0.20	p>=0.05	
L30	During his most recent period of heavy drinking, what was the maximum quantity of spirits drunk?	P	4	0	5	4.00	p<0.05	proxy tends to report larger quantities

j 'P' indicates that proxies tend to over-report relative to indexes. 'I' indicates that indexes tend to over-report relative to proxies



Q	Question text	Proxy or index over-report?	Discordant pairs proxy> control (n)	Discordant pairs control> proxy (n)	Concordant pairs (n)	McNemar's chi squared	p value (1df)	Comment
L31	During his most recent period of heavy drinking, did he drink any other alcoholic substances?	P	3	0	9	3.00	p>=0.05	no significant direction of disagreement
L32	Has he been arrested because of being drunk during the past year?	P	29	27	906	0.07	p>=0.05	
L33	Does he currently drink more, less or about the same as one year ago?	P	255	143	557	31.52	p<0.001	proxy tends to report more drinking now compared to one year ago
L34	Does he currently drink more, less or the same as one month ago?	P	155	144	644	0.40	p>=0.05	
L35	Has there been any period when he drank heavily other than during the past 12 months?	P	152	147	801	0.08	p>=0.05	
L36	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	P	33	27	1071	0.60	p>=0.05	
L37	Did he get such help during the past year?	-	7	7	119	0.00	p>=0.05	
L38	Has he ever been taken to a sobering up centre?	P	98	57	948	10.85	p<0.001	proxy more likely to answer in the affirmative
L39	Was this during the past year?	P	34	17	377	5.67	p<0.05	proxy more likely to report that this was during the past year

\* 'p' indicates that proxies tend to over-report relative to indexes. 'I' indicates that indexes tend to over-report relative to proxies

**Table 7.3** *Number of discordant and concordant index-proxy responses for tobacco, socio-economic and health related questions*

Q	Question text	Proxy/ index over- report? <sup>1</sup>	Discordant pairs proxy> control (n)	Discordant pairs control> proxy (n)	Concordant pairs (n)	McNemar's chi squared	p value (1df)	Comment
M1	Is he a current smoker?	I	10	29	655	9.26	p<0.05	proxy more likely to say 'never-smoker' than 'ex-smoker'
M2	How many years ago did he stop smoking regularly?	P	13	8	811	1.19	p>=0.05	
M4	When he smoked, how many per day was usual?	I	97	185	1039	27.46	p<0.001	proxy more likely to report a lower number smoked per day
M5	How old was he when he started smoking regularly?	-	87	93	616	0.20	p>=0.05	
M6	Have his parents ever smoked?	I	39	64	673	6.07	p<0.05	proxy more likely to report that neither had smoked
F1	What is his level of education?	P	93	59	905	7.61	p<0.05	proxy tends to report higher level of education
F3	Is he in regular paid employment?	P	24	17	641	1.20	p>=0.05	
C14	Does his household own a car?	I	33	55	640	5.50	p<0.05	proxy tends to answer in the negative
J8	Is he registered disabled?	-	1	1	400	0.00	p>=0.05	
K1	Has he had any broken bones in the past year?	-	18	18	538	0.00	p>=0.05	
K2	Does he usually cough in the morning?	P	313	142	621	64.27	p<0.001	proxy tends to report higher frequency
K3	In the past few months, could he climb up a flight up of stairs without becoming breathless?	I	47	72	361	5.25	p<0.05	proxy tends to report worse ability to do this

<sup>1</sup> 'P' indicates that proxies tend to over-report relative to indexes. 'I' indicates that indexes tend to over-report relative to proxies

#### 7.4.5 Do attributes of the index-proxy relationship improve agreement?

Having examined overall index-proxy agreement within control households for the range of selected questions, these data provide an opportunity to extend the analyses carried out in the previous chapter, and further investigate whether attributes of the index-proxy relationship affect the observed levels of agreement.

Loglinear modelling, as described earlier and in Chapter 5, was used to formally assess the difference in index-proxy agreement observed when using proxies included in subsets compared with proxies excluded from subsets defined by characteristics of the index-proxy relationship. For each subset,  $\tau$  coefficients represent the magnitude of the difference in agreement between types of index-proxy pairs included and excluded from each subset over a range of questions. These coefficients are displayed in Table 7.4, along with the p-values for Wald tests of the null hypothesis that the true value does not significantly differ from 0.

It is clear that very few significant results are obtained, with only a handful of  $\tau$  coefficients being statistically significant with reference to a critical p value of 0.05. Application of Bonferonni's correction<sup>(138)</sup> to this table of multiple statistical tests results in almost all values emerging as non-significant, using an adjusted critical p-value of  $0.05/(44*4) = 0.0003$ . In general, no particular pattern is observed by either question or subset, although there are a small number of results which are of interest.

Table 7.4  $\tau$  and p-value for the comparison in agreement distribution of index-proxy reports, comparing those pairs excluded from each subset with those included in the subset

Q	subset 1	p value	subset 2	p value	subset 3	p value	subset 4	p value
	$\tau$		$\tau$		$\tau$		$\tau$	
L1	-0.35	0.50	0.35	0.41	-0.45	0.38	-0.20	0.66
L2	-0.29	0.63	-0.95	0.03	-0.30	0.61	-1.22	0.01
L3	-0.62	0.26	0.24	0.55	-1.14	0.02	0.10	0.80
L4	4.17	0.17	-0.63	0.58	0.97	0.54	0.56	0.67
L5	-0.80	0.22	0.41	0.43	-0.20	0.77	-0.88	0.09
L6	-0.20	0.76	0.23	0.66	1.12	0.13	-1.43	0.01
L7	-0.10	0.89	0.37	0.54	-1.23	0.08	-0.24	0.67
L8	-0.66	0.63	0.75	0.68	-1.83	0.15	-0.28	0.88
L9	-0.27	0.66	0.34	0.45	-0.89	0.08	-0.25	0.60
L10	-0.81	0.21	-0.30	0.57	-1.16	0.14	-1.00	0.08
L11	0.05	0.93	-1.10	0.02	-0.92	0.10	-0.01	0.98
L12	-0.70	0.23	-0.36	0.50	-0.73	0.25	-0.56	0.25
L13	-1.18	0.11	0.23	0.69	0.15	0.87	-1.12	0.15
L14	-0.10	0.87	-0.30	0.51	0.16	0.79	-0.31	0.53
L15	0.39	0.49	-0.07	0.87	0.34	0.56	-0.42	0.39
L16	0.31	0.68	-0.33	0.53	-0.26	0.75	-0.26	0.68
L17	-0.50	0.39	-0.30	0.51	0.66	0.34	-0.62	0.19
L18	-0.46	0.46	-0.82	0.07	-0.36	0.55	-0.90	0.06
L19	-0.21	0.71	-0.64	0.14	-0.12	0.85	-1.42	0.00
L20	0.54	0.71	-0.46	0.51	1.40	0.35	0.78	0.37
L21	-0.50	0.70	-1.10	0.08	6.71	0.13	-0.98	0.34
L22	-0.32	0.76	-0.43	0.55	1.12	0.42	-0.61	0.46
L23	0.55	0.37	-0.16	0.72	1.69	0.02	-0.29	0.50
L24	-0.05	0.92	-0.21	0.59	0.08	0.88	-0.39	0.33
L25	1.08	0.34	0.67	0.46	-0.10	0.95	-0.71	0.41
L32	-0.51	0.58	-1.43	0.05	1.76	0.41	-0.71	0.33
L33	-0.39	0.48	-0.33	0.41	-0.08	0.87	-0.35	0.42
L34	-0.64	0.28	0.12	0.79	-0.75	0.18	-0.04	0.94
L36	-1.11	0.25	0.12	0.88	-0.68	0.59	0.93	0.43
L38	-0.42	0.53	-0.24	0.62	0.25	0.71	-0.14	0.82

Q	subset 1 $\tau$	p value	subset 2 $\tau$	p value	subset 3 $\tau$	p value	subset 4 $\tau$	p value
M1	-5.21	0.00	-0.63	0.62	-2.83	0.03	-1.47	0.20
M2	-1.47	0.40	-1.94	0.17	-3.24	0.06	-3.99	0.03
M3	-2.53	0.12	-1.65	0.07	-1.99	0.14	0.17	0.89
M4	0.03	0.97	-0.10	0.85	-1.02	0.14	-0.71	0.14
M5	-0.60	0.40	-0.75	0.17	-0.48	0.46	-1.38	0.01
M6	-0.47	0.57	-0.02	0.98	-0.54	0.54	-4.81	0.08
E15	-	-	-0.21	0.92	-4.26	0.09	-1.02	0.62
F1	-0.18	0.81	-0.87	0.12	-2.52	0.00	-0.59	0.34
C14	-	-	-	-	-	-	-	-
F3	-1.15	0.39	-1.40	0.16	-2.37	0.29	-0.80	0.45
J8	-	-	-	-	-	-	-	-
K1	1.18	0.58	-1.33	0.15	-1.74	0.24	-0.58	0.55
K2	-0.44	0.50	-0.33	0.51	-1.00	0.19	-0.30	0.54
K3	0.64	0.50	1.63	0.04	1.10	0.23	0.06	0.94

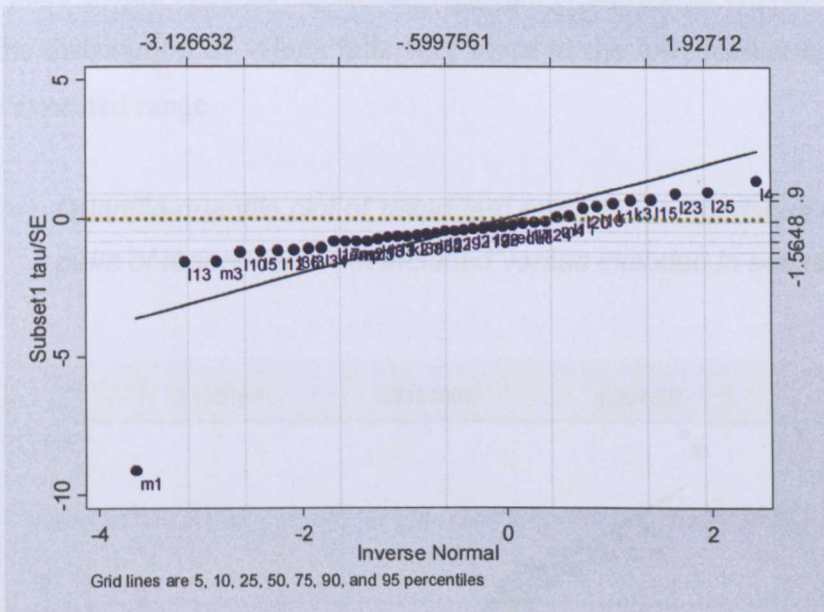
Whilst a broad range of absolute values for  $\tau$  is observed in Table 7.4, most values fall close to 0, indicating no difference between pairs, and a very small number are statistically significant, indicating a statistical difference in agreement between pairs.

Quantile-quantile plots of  $\tau$ /standard error were drawn in order to illustrate whether there is any overall tendency for systematically better or worse agreement between index-proxy pairs within each subset compared with those excluded from each subset, and to help identify any interesting outliers. These plots are presented in Figure 7.5-Figure 7.8.



Figure 7.5 Quantile-quantile plot of  $\tau$ /standard error, for comparisons between pairs of respondents not included versus included in subset 1<sup>m</sup>

In examination of subset 1, the value of  $\tau$ /standard error for most questions when

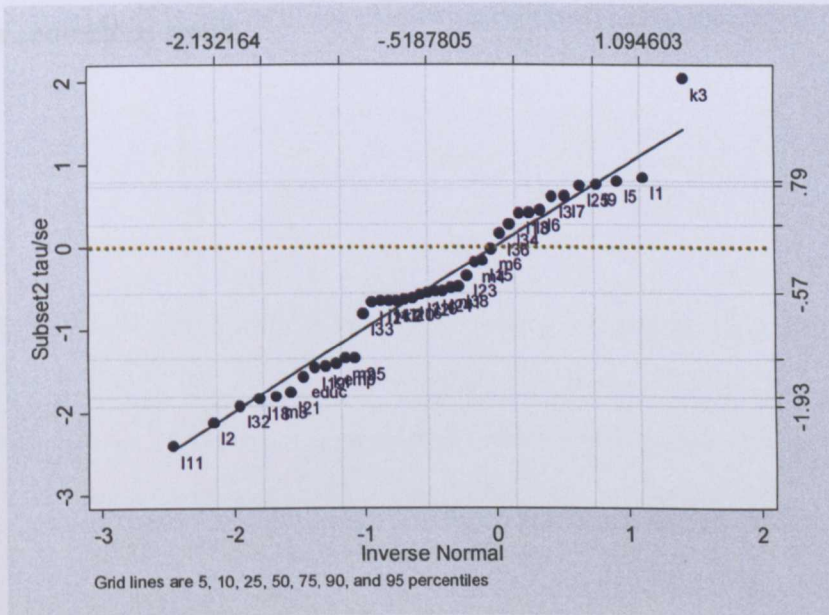


comparing pairs included to pairs excluded falls below 0 (-0.60, 95% CI -1.08, 0.11), indicating a very slight tendency for proxies who reported cohabiting with the index for at least 5 years to agree more closely with their index to those who did not report cohabiting for at least 5 years. Examination of the values in Table 7.4, and a test of the binomial proportions of the sign of  $\tau$ , for which the lower boundary of the confidence interval approaches the null value of 0.5 (0.55-0.83), provide weak evidence in support of this tendency. The result for question M1 is an outlier, with a z-value ( $\tau$ /standard error) falling far below the expected value in Figure 7.5, so much so that it has influenced the fitted line away from what is clearly a normal distribution. This question, ‘Is the man a current smoker?’ is clearly much better reported by those proxies included in the subset defined by the duration of index-proxy cohabitation relative to the index themselves, than by those proxies excluded from this subset. Closer examination of the raw data revealed that of those pairs not

<sup>m</sup> Subset 1 comprises index-proxy pairs for which the proxy reports having cohabited with the index for at least 5 years

included in subset 1, only 1 pair was discordant, with the proxy reporting that the index had never smoked, although the index themselves reported being a ex-smoker. This particular combination of responses was actually the most frequent among the discordant pairs within subset 1. If the above graph is replicated excluding question M1, then the distribution of values falls very close to the line, indicating no results outside the expected range.

Figure 7.6 Quantile-quantile plot of  $\tau$ /standard error, for comparisons between pairs of respondents not included versus included in subset 2<sup>n</sup>



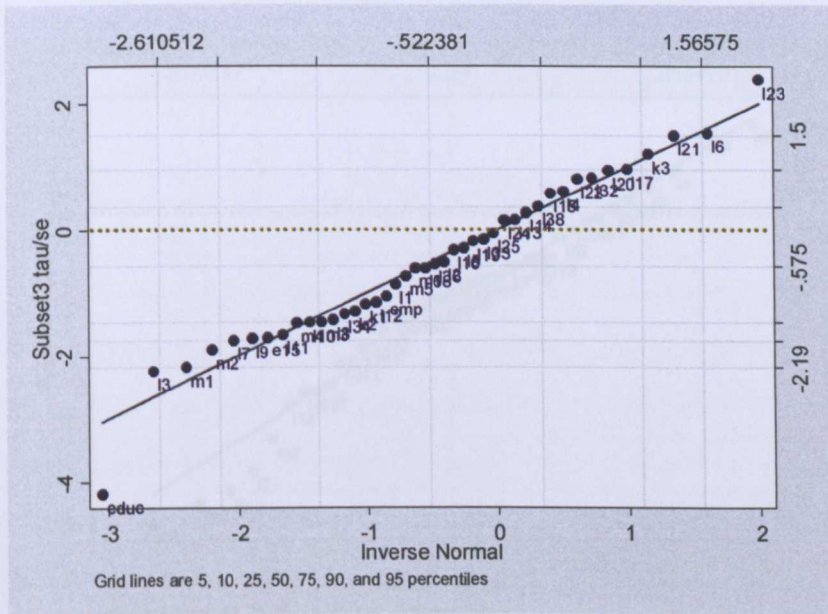
In examination of subset 2, the vast majority of questions appear to be approximately normally distributed around a mean difference which lies below 0 (-0.36, 95%CI - 0.60, -0.12), indicating a tendency for a difference in index-proxy agreement among those included and excluded from subset 2. From Table 7.4, it is observed that there is a slight tendency for  $\tau$  values to be negative. A confidence interval for a binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number of values (0.50-0.80) borders on the null value of 0.5 and has a high upper

<sup>n</sup> Subset 2 comprises index-proxy pairs for whom the proxy reports ‘very good’ or ‘extremely good’ knowledge of the index

limit, indicating that those pairs for which the proxy reported 'very good' or 'extremely good' knowledge of the index agree slightly more closely with one another than those excluded from the subset. One question emerges as an interesting outlier: there is some indication that the value for question K3, 'In the past few months, could he climb up a flight up of stairs without becoming breathless?', providing some evidence that those excluded from the subset actually agree more closely with their index than those included. It is also noticeably discontinuous from the question before, L1. Examination of the raw data for this question does not reveal any particular bias in the distribution of either concordant or discordant pairs, indicating that once again, it is small variation in the discordant pairs which has caused this anomalous result.



Figure 7.7 Quantile-quantile plot of  $\tau$ /standard error, for comparisons between pairs of respondents not included versus included in subset 3<sup>o</sup>



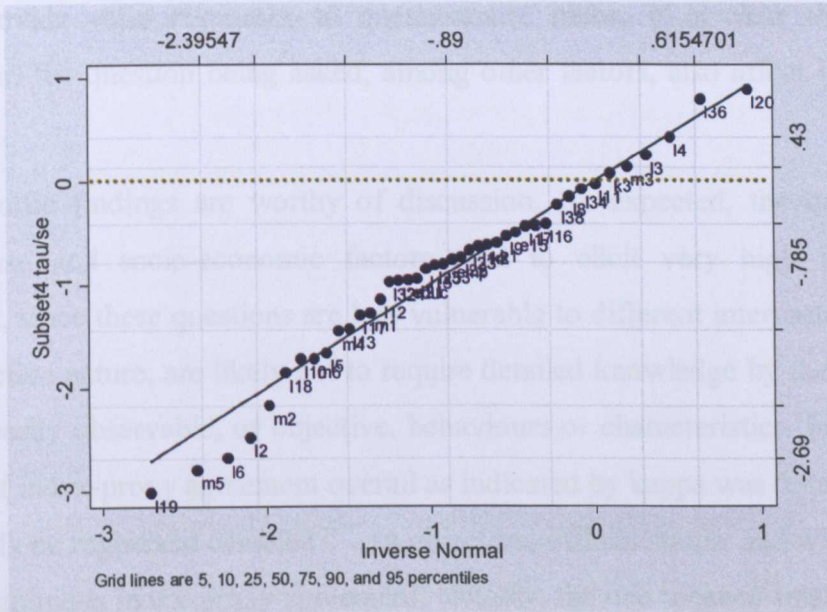
Similarly to subset 2, the questions are approximately normally distributed around a mean slightly below 0 (-0.52, 95% CI -0.92,-0.13). From Table 7.4, it can be seen that values for  $\tau$  are quite evenly distributed above and below zero, indicating no particular tendency – even within the expectations due to chance – for those proxies reporting at least daily contact with the index to agree more closely with the index to those reporting less frequent contact. This is clearly confirmed by the confidence interval for a binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number of values which spans a value of 0.5, indicating no overall difference in the proportion of values (0.48-0.78). An interesting outlier is the question on education level of the index, which those included in the subset clearly report better than those excluded.

The current chapter tests index compliance in comparison with a selected against which to validate the compliance of proxy interviews. While some findings have emerged regarding this, it is clear that the data is not yet sufficient to draw any conclusions.

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<sup>o</sup> Subset 3 comprises index-proxy pairs for which the proxy reported at least daily contact with the index

Figure 7.8 Quantile-quantile plot of  $\tau$ /standard error, for comparisons between pairs of respondents not included versus included in subset 4



Finally, within subset 4, the value of  $\tau$ /standard error for the vast majority of questions here are approximately normally distributed around a mean which falls almost one standard deviation below 0 (-0.89, 95% CI -1.18,-0.60), indicating an overall tendency for spouses to agree more closely with the index than non-spouses. Table 7.4 suggests that there may be a tendency for spouses to agree more closely overall with the index than non-spouse proxies, and this is confirmed by a binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number of values, which lies clearly above a null result of 0.5 (0.62-0.92).

## 7.5 Discussion

The current chapter uses index responses to questionnaire items as a reference against which to validate the responses of proxy informants. Some clear findings have emerged regarding which questions elicit high index-proxy agreement, along with an indication of the directionality of disagreement, where it arises. This chapter also provides important insights into which types of proxy provide more valid responses with respect to index responses.

### *Question type and agreement level*

The agreement between index and proxy reports about the same subject varies widely by question. Whilst it has already been established that proxies can, to some extent, provide valid responses to questionnaire items, it is clear that specific attributes of the question being asked, among other factors, also affect index-proxy agreement.

Some specific findings are worthy of discussion. As expected, the questions on tobacco use and socio-economic factors tend to elicit very high index-proxy agreement, since these questions are less vulnerable to different interpretation due to their objective nature, are likely not to require detailed knowledge by the proxy, and relate to easily observable, or objective, behaviours or characteristics. For example, the highest index-proxy agreement overall as indicated by kappa was obtained for the question 'Is he registered disabled?' - an objective, official status, and which elicited almost unanimous index-proxy agreement. Notably, the one tobacco-related question which elicited only 'good' agreement asked about quantity of cigarettes smoked, arguably the question requiring the most detailed knowledge. This is a clear indication that questions asking about quantity of consumption tend not to be well reported by proxies.

The application of the methods used in this chapter to index-proxy paired responses of tobacco use-related questionnaire data and other socioeconomic/health items is a useful approach to validate the appropriateness of these methods for evaluation of proxy response quality for alcohol-related questionnaire responses. As previously discussed, smoking is not generally regarded to be as sensitive a subject area as alcohol, especially among adult males, so reporting of tobacco use is likely to be free of some of the biases we would anticipate encountering with respect to alcohol reporting<sup>(49-51,53-57)</sup>. The findings presented here inspire confidence in the methods, as the kappa coefficients for agreement are generally in accordance with what is expected given the findings of the literature review in Chapter 1, and indicate that proxies can be valid respondents under certain conditions. These findings suggest that where validity is found to be poor in the investigation of agreement for alcohol-related questions, that this is an indication of those specific questions eliciting poor agreement, rather than being a general weakness in the use of proxies.

The few questions relating to alcohol showing particularly high index-proxy agreement include those asking on which day beer, wine and spirits are consumed, whether surrogates are ever consumed, and two questions about professional help for an alcohol problem. It could be argued that these are particularly easy for proxies to observe, all relating to broad behaviour patterns, and not requiring detailed knowledge of the index's behaviour. The latter three questions refer to quite extreme behaviours or events related to hazardous drinking in the index, and as alluded to in Chapter 6, the observed agreement is heavily weighted by the large number of agreements on negative responses.

The questions on alcohol use which show the lowest agreement were expected to relate to behaviours which are not easily observable by the proxy, which require detailed knowledge of specific behaviours, or which are very subjective. Indeed, the more subjective questions in these data elicit the lowest agreement. For example, the question 'How often does he fail to fulfill his family or personal obligations due to drinking alcohol?' is one which could plausibly draw quite different responses from an index and a proxy, due to their subjective assessment of events and interpretation of the question. Question L24, about the place where the man drinks alcohol, is a good example of a question about a behaviour which is difficult for proxies to observe since it occurs, by definition, away from home, hence the poor individual-level agreement in the whole dataset and for all subsets examined. The same applies to the question 'Does he ever drink spirits together with either beer or wine at the same sitting?' – where once again the proxy is unlikely to be in a position to know the answer with certainty. Questions L33-L45 ask whether the man currently drinks more, less or about the same as one month/year ago. The 'fair' agreement observed is not surprising, and reinforces the findings of the literature that particularly evaluative questions will elicit poor index-proxy agreement. The low kappa observed for question L22 ('Does he ever go to sleep at night without taking his clothes off because of being drunk') and other similar questions may simply be because due to their very nature, the index themselves does not recall these events.

The key limiting factor with respect to agreement for many of these questions is the attempt to obtain detail which the proxy is simply not able to observe, regardless of whether the proxy themselves is aware of their own lack of knowledge.



### *Over- and under-reporting of alcohol and other factors*

The investigation presented in this chapter regarding the direction of misclassification in indexes relative to proxies lends support in general to the theory that controls tend to under-report their own alcohol consumption and alcohol-related behaviour relative to proxies. Some specific results of interest emerge.

Almost without exception, proxies overestimate alcohol-related behaviour of the index relative to the index himself: proxies report more frequent drinking of beer, wine and surrogates, answer in the affirmative for a number of questions which indicate heavy alcohol use, such as ‘Does he ever drink spirits together with either beer or wine at the same sitting?’, ‘Does he ever drink large quantities of spirits without also eating some food?’, ‘Does he ever drink alcohol before noon?’, ‘Has he had one or more episodes of *zapo* in the past year?’, ‘Has he ever been taken to a sobering up centre?’. Proxies also report greater frequency of other such behaviour relative to the control: ‘How often does he become excessively drunk?’. This is in line with the literature review on the validity of proxy responses presented in Chapter 1.

At odds with this first finding, and yet in line with expectations related to poor reporting of detailed questions, it is interesting to note that for a range of other questions, proxies display a tendency to under-report relative to the index. Some such questions relate to *quantity* of beverages consumed, either usual or maximum quantity of beer and spirits on one occasion. One plausible explanation for this tendency is that asking about an absolute quantity of beverage consumption immediately introduces an element of guesswork in response which is subjective in nature, rather than the previous classes of question which all ask about more observable *frequency* or whether or not a particular behaviour is displayed at all, and proxies tend – in general - to wish to err on the side of caution, favourably portraying the index. This, it could be argued, applies most starkly for questions about quantity of alcohol consumption.

As discussed in Chapter 6, it is conceivable that the controls themselves are incorrectly self-reporting their own alcohol-related behaviour and thus a comparison of the proxy response with the control’s own response cannot provide any

information on whether the proxy respondent is ‘correctly’ reporting the exposure. There are well-documented issues associated with using the control data as gold standard, especially for alcohol-related questions. There is a widely held belief that when comparing proxy and self-reports of alcohol consumption, the respondent reporting *more* consumption – usually the proxy respondent - is likely to be more accurate. This is based on the underlying premise that a respondent is more likely to deny their own consumption than a proxy, thereby rendering proxy reports closer to the truth. However, over-reporting by indexes is also possible, which is observed for some questions examined here, such as questions about usual and maximum quantity of beer, wine and spirits consumed on one occasion. Lower reporting by proxies is often explained by an assumption that proxies are mis- or under-informed: over-reporting by index respondents is not usually considered as an explanation for lower proxy reports. However, there is some evidence to suggest that this is indeed possible and should therefore not be dismissed<sup>(49,50)</sup>. Midanik states that despite the widely held view that over-reporting by subjects about their own drinking is almost never seen as possible, there is evidence from other fields such as drug abuse that over-reporting in self reports does occur, and is related to how respondents intend to portray themselves<sup>(49)</sup>. This will of course vary across members of a study population, leading to inconsistency in terms of the relative under/over reporting of self compared with proxy reports. Indeed, this phenomenon has been noted elsewhere, as illustrated by a comment made by Schmidt in a personal communication with Pernanen, “It has also been observed that at least in certain interview situation (e.g. when seeking treatment) some alcoholics report daily consumption figures which are physiologically impossible and would result in death”.<sup>(52)</sup>

It is noted that questions on tobacco use sustain the tendency for proxies to provide more conservative responses than indexes, and extending this hypothesis, there may be a similar motivation driving the proxy tendency to overestimate level of education of the index. Regarding this latter question, an alternative explanation that the proxy has been deliberately misinformed by the index cannot be dismissed. Conversely, two of the three questions on health status of the index, ‘Does he usually cough in the morning?’, and ‘In the past few months, could he climb up a flight of stairs without

becoming breathless?', both tend towards proxy underestimating the health of the index relative to the man himself. It is possible this is because proxies tend towards under-report of the true situation. More likely, however, is that indexes consider themselves to be healthier than they are. On the whole, the minimal magnitude of directionality in questions about socioeconomic factors and tobacco use is not unexpected, since these questions tend to elicit high index-proxy agreement.

### *Are spouses the most valid informants?*

Exploration of the four subsets defined by attributes of the index-proxy relationship allowed an empirical investigation of whether the quality of that relationship impacts on the validity of proxy responses elicited.

The absence of substantial differences when examining kappa coefficients for each of the four subsets is not surprising. As already commented in section 7.4.3, the size of these four nested subsets relative to the whole sample dictates that even if those within the subsets agree more closely with the index than those excluded, the exclusion of a small number of worse respondents can have little effect on observed agreements. This is a limitation of these data, whereby in deliberately selecting the best available proxy for interview in every household, the proportion of those who have less desirable characteristics is small, making this type of analysis difficult to interpret.

However, the use of loglinear modeling was more revealing, overcoming this limitation. By enabling a formal comparison of those included versus those excluded, the results were both more striking and more convincing. Table 7.4 which presents test findings of the null hypothesis that index-proxy pairs within a subset display similar overall agreement to index-proxy pairs excluded from a subset, contains the outcomes of multiple statistical tests, which increases the probability of Type 1 errors (false positives), that must be taken into account when interpreting these findings. A Bonferoni correction to address this, helping to avoid the possibility of over-interpreting chance findings<sup>(138)</sup> is not universally supported, with some researchers arguing that the method can create more problems than it solves<sup>(139)</sup>. Regardless, in this chapter multiple statistical tests were carried out, which undoubtedly increases the possibility of attributing too much importance to a proportion of the results, and

the results were therefore interpreted after a Bonferroni correction to the critical p-value used to assess significance.

Overall, the results were most remarkable for their lack of support for the hypotheses that certain index-proxy types would result in more valid proxy responses with respect to the index. However, it did strongly emerge that spouses tended to agree more closely with the index than non-spouses, a finding in line with the general consensus in the literature, as described in Chapter 1.

### *Limitations of this study*

There are a few limitations associated with the methods employed in this chapter, and with the capacity of this analytic dataset to address the questions being posed.

These data comprise a limited number of observations which affects the precision of statistical tests carried out, particularly for some of the restricted subsets defined by proxy type. Additionally, for certain questions there are particularly low numbers of control-proxy paired responses on which calculations are based, especially in specific response categories. Conversely, for many questions there are a very large number of responses in the category at one or the other extreme of the expected distribution, making agreement appear artificially high. Thus, in many cases kappa coefficients - which are sensitive to addition and subtraction of individual households - are particularly low or high, or imprecise as calculations are driven by an apparent imbalance which is possibly an artifact of these data.

Since index data are used as reference, the analyses presented here could only be carried out using control-proxy respondent pairs as no index source for case subjects exists. Therefore the findings presented here should be interpreted with caution, as they cannot necessarily be generalized to case populations.

Finally, in exploring the direction of disagreement between index and proxy for specific questions, the interpretation of McNemar's test statistic is limited by the simple fact that for questions with strong index-proxy agreement there is, by definition, a small proportion of disagreements, meaning there may be low power to detect a significant result - depending on the absolute number of responses for any particular question. This means that differential bias for questions which are



generally reported well by proxies relative to the index may not be apparent. In contrast, questions with low index-proxy agreement are those which are least desirable for use in future questionnaires due to the compromises in data quality this would entail, and yet these are the questions for which the direction of proxy disagreement relative to the index is most transparent.

### *Concluding comments*

Taking these limitations into consideration, the results presented clearly indicate that proxies are in general able to provide broadly valid responses relative to the index response, provided questions are designed with the findings of the literature review in mind – that questions be clearly defined, ask about easily observable behaviours, and are not subjective.

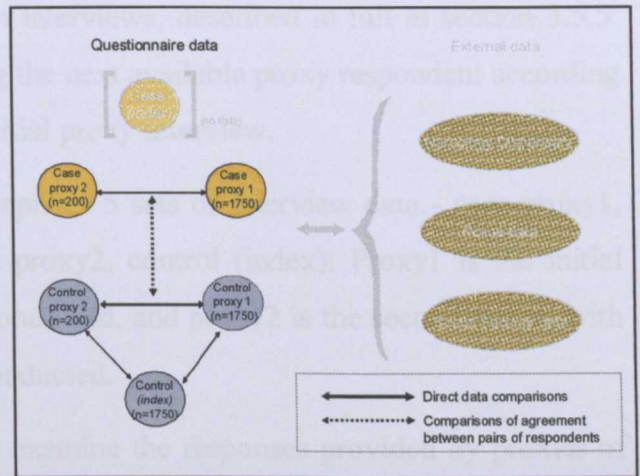
With respect to the importance of the index-proxy relationship it emerged that, provided proxies are selected according to a few simple screening questions which determine they have reasonably good knowledge of the index (see Chapter 3 for details), then further restriction according to attributes of the index-proxy relationship results in little additional improvement to index-proxy validity. This absence of significant findings with respect to the effect of subset is an interesting result in itself, in terms of support for the proxy selection protocol employed by the Izhevsk Family Study.

However, the restriction to spouses only as proxies is a clear exception. It clearly emerged that spouses tended to agree more closely with the index than non-spouse proxies. This is in line with the findings of the previous chapter and the consensus in the literature.

Whilst these analyses are interesting in the conclusions they offer, the methods used in this chapter are unable to account for any possible confounding of the agreement between the index and proxy reports by characteristics of the subject. Therefore, *Chapter 8* will approach the issue of which proxy provides the most valid responses in a different way. This will be done by exploring the effect of proxy type among households that have more than one type of proxy available, thereby adjusting for unknown ‘household effects’.

## Chapter 8 Agreement between proxies within the same household

Investigations in previous chapters have provided some evidence that wives, girlfriends and partners tend to agree more closely with the index than other proxies, thus supporting the consensus in the literature that spouses should be used as proxies wherever possible (Chapter 1). An important limitation with respect to interpretation of previous analyses is that the proxy respondent available in each instance is not randomly selected, but is a function of the household's, and therefore of the specific index's attributes. The question is thus raised regarding the reasons driving earlier findings: is the differential in response validity attributable to qualities of different types of proxy, or is it due to properties of informant households *per se*?



This chapter addresses this issue by examination of the responses provided by two proxies within a single household. This approach removes any confounding effect of measurable and unmeasurable attributes of the households and index, thereby providing a less biased assessment of the effect of *proxy* type on proxy response validity.

### 8.1 Summary of chapter contents

This chapter investigates the hypothesis that the spouse is a preferable choice of proxy to the next best available proxy, according to the Izhevsk Family Study protocol for proxy respondent selection. Initially, the agreement between two proxies in a single household is examined within case and control households. The difference in agreement between an index and each of two proxies interviewed within single

control households is then investigated in order to explore the impact of proxy type on agreement. Finally, a formal investigation of the agreement between two within-household proxies within case compared with control households is conducted in order to determine the importance of case/control status of the index in this regard.

## **8.2 Methods**

Within the data collected for the Izhevsk Family Study, there is a sample of 200 case and 200 control households for whom an additional proxy interview (a 'validation' interview) was carried out. Validation interviews were conducted according to exactly the same protocol as the main interviews, described in full in section 3.5.5. Proxy selection was made by selecting the next available proxy respondent according to the list of preference used for the initial proxy interview.

The data analysed in this chapter comprises 5 sets of interview data - case proxy1, case proxy2, control proxy1, control proxy2, control (index). Proxy1 is the initial proxy with whom an interview was conducted, and proxy2 is the second proxy, with whom the validation interview was conducted.

These data provide an opportunity to examine the responses provided by proxies of different types within households in comparison to each other and, within control households, to the index for a range of questions about alcohol consumption, tobacco use, socioeconomic factors and health. Since pairs of proxies are drawn from single households, there is automatic adjustment for any unmeasured or measured index or household attributes that may affect proxy response validity. This method is informative, therefore, regarding the variation in response obtained when using proxies of different types. In this context, it is possible to investigate whether proxy type (spouse/non-spouse) affects reporting, and to examine any differences between case and control proxy pairs in this regard.

### **8.2.1 Does proxy type affect the response obtained?**

In order to investigate the importance of proxy type, initially the concordance between pairs of proxies within households was examined using Cohen's kappa coefficient for the same range of questions employed in previous analyses. This was

done separately for case and control households for which there was a first proxy interview with the index's spouse and a validation interview with an additional proxy, in order to remove likely effects of whether the index had recently died. Kappa was weighted using one of the two STATA standard weightings available (defined in section 5.3.2) where question response categories were ordinal, and unweighted otherwise. Strong agreement between proxies indicates that different proxy types provide similar responses regardless of household attributes – i.e. it is the household which produces the proxy response, not the type of proxy. Weaker agreement indicates that different proxy types provide different responses to questions, after adjustment for any unmeasured attributes of the household which may affect their responses. In this case, proxy type is more important. This latter finding would provide support for the findings in Chapter 7 which showed that the spouse tends to be in greater agreement with the index than other proxies, whilst the former would contradict these conclusions.

Agresti's loglinear model was then used to examine the difference in association between the control and proxy1, and the control and proxy2 within a fixed group of households where proxy1 was the spouse and proxy2 was the next best available respondent. As described above, the results of this analysis is more informative about the effect of proxy type on response than analyses carried out in previous chapters, since it controls for characteristics which differ between households, which may confound the response given by proxy1 in addition to any effect of proxy type.

### 8.2.2 Does case-control status of the index affect proxy response?

As discussed in Chapter 5, Cohen's kappa coefficient does not lend itself to formal comparison and it is not possible to reliably deduce whether the case/control status of the index was an important factor affecting the importance of proxy type from the first analysis presented in this chapter. Therefore, Agresti's loglinear model was used to formally investigate the difference in internal agreement between proxy1 and proxy2 in case versus control households. As before, this analysis was restricted to households in which proxy1 was the spouse. This method is described in more detail in Chapter 5.

### 8.2.3 Examination of households from which a validation interview was obtained

In order to determine the generalisability of results of the analyses in this chapter, it was important to establish that the subset of households analysed did not differ in their basic characteristics from those households which were eligible to provide a validation interview but did not, and from all other households examined in this thesis.

The characteristics of indexes from households in which a validation interview was successfully obtained were compared firstly with households in which a validation interview was theoretically possible due to household composition, and was attempted but not obtained, and secondly with the rest of the sample. The time period in which first proxy interviews were carried out was identified for those households in which there was also a validation interview, and from this and the household composition reported by proxy1 in the initial interview it was possible to identify those households which were eligible for a validation interview at this point. Households whose composition was unknown (unreported) were excluded. Cross tabulations of the samples in which a validation interview were/were not conducted among eligible households were carried out by age, education level, employment status and narcology registration status of the index. A matrix of proxy1 type against proxy2 type was obtained among these households.

Agresti's loglinear model<sup>(128)</sup>, described in 5.3.3 on page 90, was used to evaluate whether the agreement between proxy1 and the control significantly differed in the eligible households in which a validation interview was obtained, compared with all households in which no validation interview was obtained.

### 8.3 Results

#### 8.3.1 Formation and description of validation interview subset

Validation interviews were carried out over a defined period of time, beginning on the 20<sup>th</sup> November 2004 and ending on the 13 June (case households) and the 7<sup>th</sup> July (control households). The corresponding first proxy interviews were carried out between 20<sup>th</sup> November 2004 and the 12<sup>th</sup> June (case households)/7<sup>th</sup> July (control households). The number of case and control households in the whole sample which could have in principle provided a validation interview was ascertained by examination of household size (Table 8.1). In 75.2% of case households in which a successful first interview was obtained, there were at least two possible proxy respondents, whilst the figure for control households was slightly higher at 84.2%.

**Table 8.1** *Number of possible proxy respondents in case/control households from which a successful first proxy interview was obtained*

n	case households		control households	
	n	%	n	%
1	324	24.8%	219	15.8%
2	404	31.0%	444	32.0%
3	313	24.0%	450	32.4%
4	153	11.7%	190	13.7%
5	72	5.5%	58	4.2%
6	19	1.5%	17	1.2%
7	14	1.1%	4	0.3%
8	0	0.0%	3	0.2%
9	1	0.1%	0	0.0%
10	0	0.0%	1	0.1%
11	0	0.0%	1	0.1%
12	1	0.1%	0	0.0%
<i>unknown</i>	4	0.3%	0	0.0%
<b>Total</b>	<b>1,305</b>	<b>100.0%</b>	<b>1,387</b>	<b>100.0%</b>

The success rate in obtaining a validation interview from eligible households was calculated (Table 8.2). This was based on the number of households comprising at least 2 proxies for which an eligible first proxy interview was carried out within this time period, as defined above.

**Table 8.2** *Number of possible proxy respondents and percentage success in obtaining validation interview in eligible case/control households for which a successful validation interview was/was not obtained*

Household size	Control households				Case households					
	Eligible households		Validation interview obtained		Eligible households		Validation interview obtained		% success	
	n	%	n	%	n	%	n	%		
2	191	40%	61	31%	32%	152	42%	60	30%	39%
3	170	36%	66	33%	39%	112	31%	69	35%	62%
4	69	15%	45	23%	65%	52	14%	34	17%	65%
5	28	6%	20	10%	71%	30	8%	24	12%	80%
6	8	2%	6	3%	75%	9	3%	8	4%	89%
7	4	1%	1	1%	25%	5	1%	5	3%	100%
8	2	0%	1	1%	50%	0	0%	0	0%	-
11	1	0%	0	0%	0%	0	0%	0	0%	-
<b>Total</b>	<b>473</b>	<b>100%</b>	<b>200</b>	<b>100%</b>		<b>360</b>	<b>100%</b>	<b>200</b>	<b>100%</b>	

As expected, the percentage success increased with increasing number of possible second proxy respondents, excluding households of size 11 for which no validation interviews were obtained from the 1 eligible control household.

In order to investigate the distribution of respondent types in these households, a matrix of first proxy and second proxy in case and control households was obtained (Table 8.3). It is clear that in the vast majority of both case and control households, the first proxy was the wife, girlfriend or partner, followed by parent. Second proxies were most commonly the son or daughter of the index in both case and control households. When the first proxy was not the wife, girlfriend or partner, the most

common combination of proxy1 and proxy2 was parent/parent. Other proxy pair combinations are sparsely distributed throughout the matrix.

Table 8.3 Distribution of proxy1 by proxy2 type in case and control households

Proxy1	Proxy2											Total
	wife girlfriend/ partner	parent	brother	sister	daughter	daughter in law	son	son in law	other relative	unrelated lodger/ friend	other	
<b>Case proxies</b>												
wife/girlfriend/partner	-	9	1	3	56	1	48	-	9	3	1	131
Parent	-	14	8	2	-	-	-	-	3	-	-	27
brother	-	2	-	-	-	-	-	-	5	-	-	7
Sister	-	8	1	-	-	-	-	-	3	-	-	12
daughter	-	-	-	-	2	-	2	1	-	-	-	5
Son	-	-	-	-	1	5	1	-	-	-	-	7
son in law	1	-	-	-	-	-	-	-	-	-	-	1
other relative	-	-	2	-	-	-	1	-	4	-	-	7
other	1	-	-	-	-	-	-	-	-	-	2	3
<b>Total</b>	<b>2</b>	<b>33</b>	<b>12</b>	<b>5</b>	<b>59</b>	<b>6</b>	<b>52</b>	<b>1</b>	<b>24</b>	<b>3</b>	<b>3</b>	<b>200</b>
<b>Control proxies</b>												
wife/girlfriend/partner	-	22	-	-	79	1	60	-	15	1	-	178
Parent	-	8	3	1	-	1	-	-	2	-	-	15
Sister	-	1	-	-	-	-	-	-	-	-	-	1
daughter	-	-	-	-	-	-	-	2	-	-	-	2
Son	-	-	-	-	-	1	1	-	-	-	-	2
unrelated lodger/friend	-	-	-	-	1	-	-	-	-	-	-	1
Other	-	-	-	-	-	-	-	-	-	-	1	1
<b>Total</b>	<b>0</b>	<b>31</b>	<b>3</b>	<b>1</b>	<b>80</b>	<b>3</b>	<b>61</b>	<b>2</b>	<b>17</b>	<b>1</b>	<b>1</b>	<b>200</b>

This dataset comprising two proxies per index provides a unique opportunity to address the question of whether spouses are more valid respondents than other types of proxy both within control households, and between case and control households.



### 8.3.2 Does proxy type make a difference? (1)

#### Within-household agreement between two proxies

In order to address this question, initially the kappa coefficients for proxy1-proxy2 agreement by question were examined. Where agreement is high, this suggests that proxy type is not important with respect to index-proxy agreement. Where agreement is low, the converse may be true.

Although kappa coefficients cannot formally be compared, the following tables provide a broad indication of the extent of agreement between proxies within each household in the light of whether or not the index has died. Tables of response distribution are provided in Appendix 7 primarily to aid in interpretation of the kappa statistics presented below (Table 8.4 and Table 8.5). The results are ordered according to the kappa coefficient observed in control households, and horizontal lines indicate the boundary between categories proposed by Landis and Koch<sup>(67)</sup> for interpretation of kappa coefficients.

Within control households, it is apparent that proxy1 and proxy2 tend to agree quite closely with one another in responding to questions related to alcohol use, with most kappa coefficients falling into and above the 'moderate' range (kappa = 0.49-0.82). A few questions elicit greater discrepancies in control proxy responses, specifically, L5 ('On which day is beer usually drunk?'), L7 ('On which day are spirits usually drunk?'), L23 ('Does he ever drink alone?'), L24 ('Does he usually drink alcohol at home or in other places?'), L33 ('Does he currently drink more, less or about the same as one year ago?'), and L34 ('Does he currently drink more, less or about the same as one month ago?') all had kappa < 0.42, which is at the bottom end of the 'moderate' range of values. The findings suggest that whilst in general, proxy-proxy agreement within control households is no worse than index-proxy agreement over the same range of questions, proxy type is, to some extent, a factor which may affect index-proxy agreement within control households for alcohol use questions.

Although question-specific kappa coefficients differ, the same broad conclusions can be drawn for case households. Proxy1 and proxy2 tend to agree quite closely with one another over most of the alcohol questions, with most kappa values falling about

0.55. However, a few kappa coefficients are quite low, suggesting the importance of proxy type with respect to responses obtained.

**Table 8.4** *Cohen's kappa coefficient to show agreement between proxy1 and proxy2 for questions on alcohol use*

Question	Controls	Cases
L25 Has he had one or more episodes of zaponi in the past year?	0.82	0.78
L36 Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	0.82	0.76
L8 On which day are other alcoholic substances usually drunk?	0.76	0.85
L4 How often are other alcoholic substances drunk?	0.75	0.82
L20 How often does he fail to fulfil his work obligations due to drinking alcohol?	0.67	0.68
L1 How often is beer usually drunk?	0.65	0.60
L38 Has he ever been taken to a sobering up centre?	0.60	0.77
L2 How often is wine usually drunk?	0.59	0.64
L3 How often are spirits usually drunk?	0.58	0.61
L12 What is the maximum quantity of beer ever drunk on one occasion?	0.57	0.56
L17 How often does he become excessively drunk?	0.57	0.59
L19 How often does he have a hangover?	0.57	0.62
L32 Has he been arrested because of being drunk during the past year?	0.57	0.66
L10 How much wine is usually drunk on one occasion?	0.56	0.57
L13 What is the maximum quantity of wine ever drunk on one occasion?	0.56	0.52
L14 What is the maximum quantity of spirits ever drunk on one occasion?	0.55	0.50
L11 What quantity of spirits is usually drunk on one occasion?	0.54	0.53
L21 How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	0.54	0.69
L6 On which day is wine usually drunk?	0.53	0.58
L16 Does he ever drink large quantities of spirits without also eating some food?	0.51	0.65
L18 Does he ever drink alcohol before noon?	0.50	0.55
L22 Does he ever go to sleep at night without taking his clothes off because of being drunk?	0.50	0.67
L9 How much beer is usually drunk on one occasion?	0.49	0.56

Question		Controls	Cases
L15	Does he ever drink spirits together with either beer or wine at the same sitting?	0.49	0.44
L23	Does he ever drink alone?	0.42	0.55
L5	On which day is beer usually drunk?	0.39	0.58
L7	On which day are spirits usually drunk?	0.37	0.48
L24	Does he usually drink alcohol at home or in other places?	0.33	0.49
L34	Does he currently drink more, less or the same as one month ago?	0.19	0.52
L33	Does he currently drink more, less or about the same as one year ago?	0.17	0.54

For questions related to smoking, agreement between proxy1 and proxy2 was consistently very high with kappa=0.77 and above for four of the six questions in control households. Question M5 ('How old was he when he started smoking regularly?') had a slightly lower kappa of 0.56, and question M4, asking about the detailed quantity aspect of smoking, had a lower kappa of 0.33. Agreement between proxies for socioeconomic factors was all within or approaching the 'almost perfect' range (kappa>0.80), but was poorer for two of the questions asking about aspects of health, K2 ('Does he usually cough in the morning?') and K3 ('In the past few months, could he climb up a flight of stairs without becoming breathless?').

In case households, however, all results indicated at least 'substantial' proxy1-proxy2 agreement except K2, for which kappa=0.53 which is still in a range indicating that proxy type was less important among cases.

**Table 8.5** *Cohen's kappa coefficient to show agreement between proxy1 and proxy2 for questions on tobacco use, socioeconomic factors and health*

Question	Controls	Cases
M1 Is he a current smoker?	0.96	0.87
J8 Is he registered disabled?	0.96	1.00
E15 What is his marital status?	0.88	0.9
F3 Is he in regular paid employment?	0.87	0.88
M3 What does he smoke most often?	0.83	0.77
M2 How many years ago did he stop smoking regularly?	0.79	0.70
F1 What is his level of education?	0.78	0.71
M6 Have his parents ever smoked?	0.77	0.84
K1 Has he had any broken bones in the past year?	0.77	0.69
C14 Does his household own a car?	0.75	0.69
M5 How old was he when he started smoking regularly?	0.56	0.72
K2 Does he usually cough in the morning?	0.47	0.53
K3 In the past few months, could he climb up a flight up of stairs without becoming breathless?	0.41	0.69
M4 When he smoked, how many per day was usual?	0.33	0.66

These results suggest that case proxies appear in general to perform better than control proxies in terms of agreement between proxy1 and proxy2, indicating that the choice of proxy in control households may be more important than in case households, especially for specific questions. Overall, however, agreement tends to be good, providing little evidence here to suggest that proxy type is an important driving factor behind proxy validity.

### 8.3.3 Does proxy type make a difference? (2)

#### Formal comparison of within-household index-proxy pairs

In order to further evaluate the importance of proxy type, a comparison of the agreement between proxy1 and the index (control) was made with the agreement between proxy2 and the index. Where there is little or no difference in the agreement between different index-proxy pairs, this is evidence that proxy type is not important and, conversely, where more substantial difference is observed in agreement, this provides evidence of an effect of proxy type.

Since direct comparisons may not be made using kappa statistics, the importance of proxy type was formally explored using Agresti's loglinear model to examine the difference in index-proxy agreement within control households which had a validation interview as well as a first interview. The households examined are therefore identical for both types of pairing, so there is automatic adjustment to some extent for characteristics of the index or household which may have influenced earlier analyses.

The results of this analysis are shown in Table 8.6. This analysis is notable for its lack of any statistically significant results. Of the questions examined, only one showed statistical evidence of differential index-proxy agreement according to proxy type. In further support of this null finding, 20 out of the 44 questions examined had positive  $\tau$  values, and the remaining were negative, resulting in a non-significant test of the null hypothesis that half the values should be of either sign. The magnitude of all coefficients was small, except for those obtained for L16 ('Does he ever drink large quantities of spirits without also eating some food?'), employment ('Is he in regular paid employment?') and K1 ('Has he had any broken bones during the past year?'). Examination of the raw data for these three questions revealed that the distributions of index-proxy agreement were heavily dominated by the large number of conservative responses, in agreement, by both index and proxy, and any difference in distribution was in the responses of a very small number of proxy respondents which explains why the differences were not detected as statistically significant, and also suggests that they are not reflections of actual differences in reporting of these questions by proxy type.

Table 8.6  $\tau$  and  $p$ -value for the difference in agreement between the index with proxy2 and the index with proxy1 in control households

Question	$\tau$	p value
L1 How often is beer usually drunk?	0.08	0.87
L2 How often is wine usually drunk?	-0.33	0.59
L3 How often are spirits usually drunk?	0.50	0.32
L4 How often are other alcoholic substances drunk?	0.02	1.00
L5 On which day is beer usually drunk?	0.59	0.35
L6 On which day is wine usually drunk?	-0.24	0.71
L7 On which day are spirits usually drunk?	0.03	0.96
L8 On which day are other alcoholic substances usually drunk?	-0.55	0.77
L9 How much beer is usually drunk on one occasion?	-0.32	0.54
L10 How much wine is usually drunk on one occasion?	0.00	1.00
L11 What quantity of spirits is usually drunk on one occasion?	-0.49	0.40
L12 What is the maximum quantity of beer ever drunk on one occasion?	-0.10	0.85
L13 What is the maximum quantity of wine ever drunk on one occasion?	-0.05	0.94
L14 What is the maximum quantity of spirits ever drunk on one occasion?	-0.31	0.59
L15 Does he ever drink spirits together with either beer or wine at the same sitting?	0.04	0.94
L16 Does he ever drink large quantities of spirits without also eating some food?	1.76	0.05
L17 How often does he become excessively drunk?	-0.74	0.22
L18 Does he ever drink alcohol before noon?	-0.50	0.42
L19 How often does he have a hangover?	-1.07	0.08
L20 How often does he fail to fulfil his work obligations due to drinking alcohol?	-0.43	0.71
L21 How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	-0.13	0.88
L22 Does he ever go to sleep at night without taking his clothes off because of being drunk?	-0.67	0.51

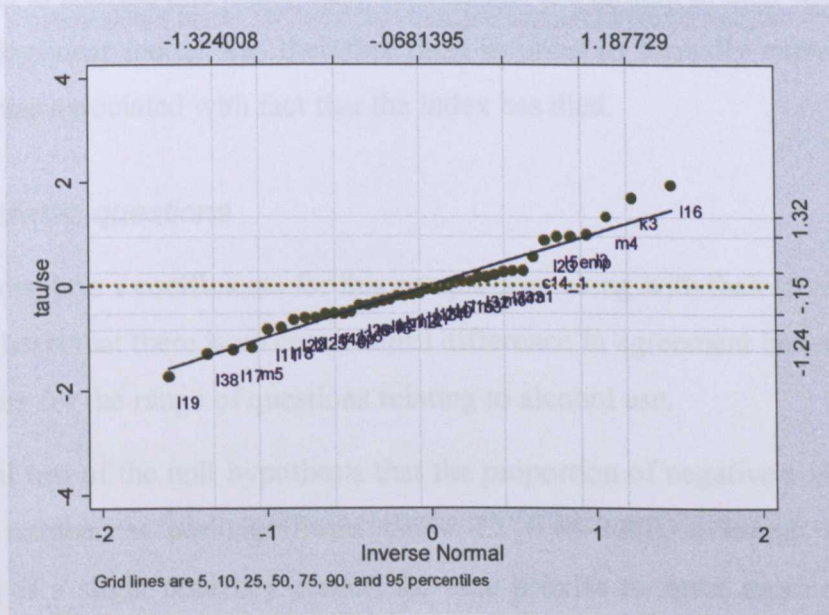
Question	$\tau$	p value
L23 Does he ever drink alone?	0.44	0.38
L24 Does he usually drink alcohol at home or in other places?	-0.03	0.95
L25 Has he had one or more episodes of zaponi in the past year?	-0.74	0.54
L32 Has he been arrested because of being drunk during the past year?	0.22	0.86
L33 Does he currently drink more, less or about the same as one year ago?	0.14	0.79
L34 Does he currently drink more, less or the same as one month ago?	0.14	0.79
L36 Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	-0.50	0.62
L38 Has he ever been taken to a sobering up centre?	-0.74	0.19
M1 Is he a current smoker?	0.43	0.78
M2 How many years ago did he stop smoking regularly?	-0.47	0.83
M3 What does he smoke most often?	0.12	0.93
M4 When he smoked, how many per day was usual?	0.85	0.19
M5 How old was he when he started smoking regularly?	-0.81	0.23
M6 Have his parents ever smoked?	0.18	0.84
E15 What is his marital status?	-0.67	0.73
F3 Is he in regular paid employment?	1.44	0.35
C14 Does his household own a car?	0.35	0.59
J8 Is he registered disabled?	-	-
F1 What is his level of education?	-0.37	0.59
K1 Has he had any broken bones in the past year?	1.63	0.09
K2 Does he usually cough in the morning?	0.08	0.87
K3 In the past few months, could he climb up a flight up of stairs without becoming breathless?	-0.33	0.59

A quantile-quantile plot of  $\tau$ /standard error (Figure 8.1) was drawn in order to illustrate whether there is any overall tendency for systematically better or worse agreement between index-spouse pairs versus index-proxy2 pairs, where proxy2 is



the next best available proxy. Additionally, this plot helps to identify any interesting outliers, indicating questions for which spouses provide particularly more or less valid responses with respect to the index when compared with the next best available proxy.

Figure 8.1 Quantile-quantile plot of  $\tau$ /standard error, for the difference in agreement between the index with proxy2 and the index with proxy1



This plot shows that the difference in agreement is normally distributed around a mean which falls close to 0 (-0.07, 95% CI -0.30, 0.17), indicating no particular tendency for either index-spouse or index-proxy2 pairs to have better overall agreement. Only a small number of questions have standardised values which approach 1.96 standard deviations away from the value of 0 and none exceed this value.

These findings suggest that neither group of proxies (spouses/non spouses) agrees more closely overall with this constant group of indexes beyond expectations due to chance. It is noted, however, that these findings which are in contrast with the previous chapter, may be attributable to the small sample size employed in these analyses.



### 8.3.4 Is there case-control bias in the effect of proxy type on response validity?

Apart from a few exceptions, based on the evidence presented in this chapter it appears that there is little advantage in using spouses as proxies in control households. The same appears to be true in case households, as case proxies 1 and 2 tend to closely agree. However, since there is no case index available against which to compare two proxies, and there are strong limitations involved in relying on kappa coefficients to address this issue, these conclusions are limited in their interpretation. Agresti's loglinear model was therefore used in order to formally explore whether there is a bias associated with fact that the index has died.

#### *Alcohol-related questions*

Table 8.7 displays  $\tau$  coefficients for this comparison, along with their p-values for the null hypothesis that there is no case/control difference in agreement between proxy1-proxy2 pairs for the range of questions relating to alcohol use.

A binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number is non-significant (95% CI 0.44-0.80), although there is an indication of a slight tendency overall for case proxies to agree more closely with one another than control proxies. This is supported by examination of coefficients in the table, which reveals that most  $\tau$  values fall close to 0, but tend to be negative. However, only three of the 30 questions examined here show statistical evidence of a difference at the 5% level, and after application of a Bonferroni correction, only one question displays a statistically significant result when using a corrected critical p value of 0.002: question L33 ('Does he currently drink more, less or about the same as one year ago?'), for which case proxies show statistically better agreement with one another than control proxies, a finding also indicated by examination of kappa coefficients in Table 8.4. Question L34, asking about change in drinking behaviour since a month ago shows weak statistical evidence of different case/control association: the magnitude of  $\tau$  does indicate a tendency for case proxies to be in stronger agreement for this question than control proxies.

Table 8.7  $\tau$  and  $p$ -value for the difference in agreement distribution of proxy1—proxy2 reports for alcohol-related questions, in control versus case households

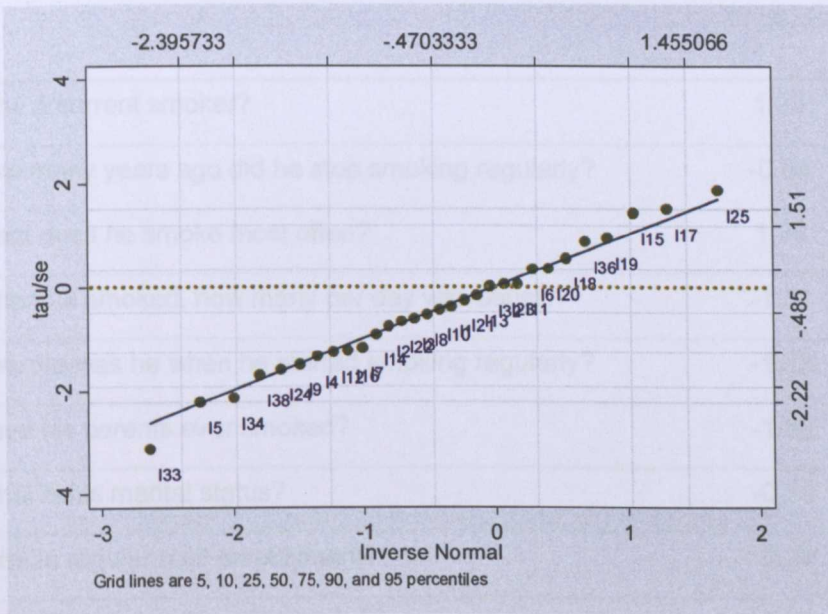
Questions	$\tau$	$p$ value
L1 How often is beer usually drunk?	-0.21	0.71
L2 How often is wine usually drunk?	-0.53	0.44
L3 How often are spirits usually drunk?	-0.34	0.53
L4 How often are other alcoholic substances drunk?	-3.93	0.18
L5 On which day is beer usually drunk?	-1.86	0.03
L6 On which day is wine usually drunk?	0.27	0.73
L7 On which day are spirits usually drunk?	-0.83	0.23
L8 On which day are other alcoholic substances usually drunk?	-1.15	0.59
L9 How much beer is usually drunk on one occasion?	-0.92	0.14
L10 How much wine is usually drunk on one occasion?	-0.31	0.66
L11 What quantity of spirits is usually drunk on one occasion?	0.03	0.96
L12 What is the maximum quantity of beer ever drunk on one occasion?	-0.77	0.21
L13 What is the maximum quantity of wine ever drunk on one occasion?	-0.14	0.86
L14 What is the maximum quantity of spirits ever drunk on one occasion?	-0.59	0.36
L15 Does he ever drink spirits together with either beer or wine at the same sitting?	0.88	0.15
L16 Does he ever drink large quantities of spirits without also eating some food?	-0.93	0.22
L17 How often does he become excessively drunk?	0.96	0.13
L18 Does he ever drink alcohol before noon?	0.34	0.58
L19 How often does he have a hangover?	0.66	0.34
L20 How often does he fail to fulfil his work obligations due to drinking alcohol?	0.40	0.73
L21 How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	-0.27	0.80
L22 Does he ever go to sleep at night without taking his clothes off because of being drunk?	-0.64	0.50

Questions	$\tau$	p value
L23 Does he ever drink alone?	0.02	0.96
L24 Does he usually drink alcohol at home or in other places?	-0.88	0.11
L25 Has he had one or more episodes of zaponi in the past year?	2.69	0.06
L32 Has he been arrested because of being drunk during the past year?	0.01	0.99
L33 Does he currently drink more, less or about the same as one year ago?	-1.85	0.00
L34 Does he currently drink more, less or the same as one month ago?	-1.33	0.03
L36 Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	0.90	0.38
L38 Has he ever been taken to a sobering up centre?	-1.28	0.09

A quantile-quantile plot of  $\tau$ /standard error (Figure 8.2) illustrates these findings. All questions are normally distributed around a mean which lies close to, but below, 0 (-0.47, 95%CI -0.91, -0.03). After standardisation, no questions emerge as important outliers. This evidence reinforces the above conclusions that there is an overall tendency for within-household proxies to agree more closely with one another in case versus control households.



Figure 8.2 Quantile-quantile plot of  $\tau$ /standard error, for the difference in proxy1-proxy2 agreement in control versus case households for alcohol-related questions



### Tobacco use, socioeconomic factors and health related questions

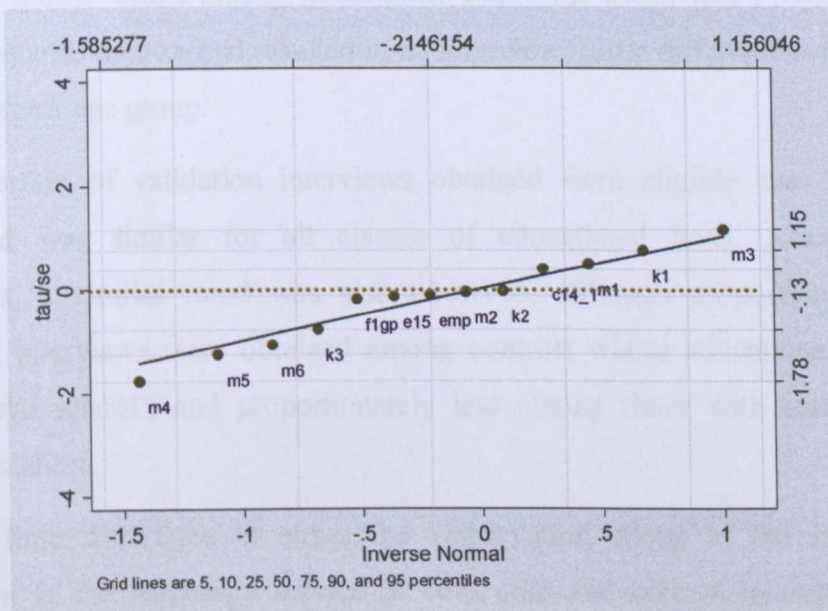
Table 8.8 displays the results of this analysis for questions relating to tobacco use, socio-economic factors and health questions. Once again, a binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number was also non-significant (95% CI 0.43-0.95) indicating no particular tendency overall for case proxies or control proxies to agree more closely with one another. This finding was supported by the fact that none of these questions showed evidence of a statistically significant difference at the 5% level. The one obvious finding from Table 8.5, that question M4 is answered differently by proxies in control households, but not in case households ( $\kappa=0.33, 0.66$  respectively), is reflected in the magnitude of  $\tau$  in Table 8.8, for which there is some weak statistical evidence in support.

**Table 8.8**  $\tau$  and  $p$ -value for the difference in agreement distribution of proxy1—proxy2 reports in control versus case households for questions related to tobacco use, socioeconomic factors and health

Question	$\tau$	$p$ value
M1 Is he a current smoker?	1.36	0.63
M2 How many years ago did he stop smoking regularly?	-0.86	0.94
M3 What does he smoke most often?	1.88	0.25
M4 When he smoked, how many per day was usual?	-1.31	0.07
M5 How old was he when he started smoking regularly?	-1.42	0.20
M6 Have his parents ever smoked?	-1.88	0.28
E15 What is his marital status?	-0.28	0.87
F3 Is he in regular paid employment?	-0.24	0.90
C14 Does his household own a car?	0.27	0.71
J8 Is he registered disabled?	-	-
F1 What is his level of education?	-0.15	0.84
K1 Has he had any broken bones in the past year?	1.04	0.46
K2 Does he usually cough in the morning?	-0.03	0.97
K3 In the past few months, could he climb up a flight up of stairs without becoming breathless?	-0.65	0.43

These results are illustrated by a quantile-quantile plot, Figure 8.3. This range of questions are normally distributed about a mean close to 0 (-0.21, 95%CI -0.72, 0.29), indicating no overall tendency for greater proxy1-proxy2 agreement in either type of household. After standardisation, M4 is no longer an important outlier, although this question lies at the tail end of the distribution, and shows a very slight departure from the expected value under the assumption of a normal distribution, approaching 1.95 standard deviations away from a null value of 0. This indicates that agreement in control proxy responses to this question differ from one another significantly more than case proxy responses.

Figure 8.3 Quantile-quantile plot of  $\tau$ /standard error, for the difference in proxy1-proxy2 agreement in control versus case households for questions on tobacco use, socio-economic factors and health



In summary, there is little statistical evidence to support any overall trend for a difference in the proxy1-proxy2 agreement in case versus control households. The only clear exceptions are two questions asking about change in alcohol consumption behaviour, for which case proxies are in closer agreement than control proxies, and one question asking about quantity of cigarettes smoked, which shows bias in the same direction.

### 8.3.5 Generalisability of this subset

In order to be able to generalise these findings to the larger dataset, it was important to establish that there were no important differences in the baseline characteristics of those households examined within this chapter (for which a validation interview was obtained) with those for which a validation interview was not obtained.

A selection of characteristics was compared between eligible households for which a successful validation interview was/was not obtained. These characteristics, (age of index, education level of index, employment status of index and narcology registration) are displayed in Table 8.9.

Age distribution differed noticeably between those eligible households in which a validation interview was/was not obtained. A greater proportion of interviews were obtained from both case and control proxy households where the index was in the oldest age group, whilst among households where the index was 35-39, fewest of those households approached resulted in an interview. Little difference was observed in the youngest age group.

The proportion of validation interviews obtained from eligible case households approached was similar for all classes of educational level. Among control households, a similar trend was also observed, although proportionately more successful interviews were obtained among controls whose educational level was 'professional school', and proportionately less among those with some/complete higher education.

There is little difference in either the employment status of the index, or in registration at the narcology service in both case and control households, when examined by households in which a validation interview was/was not obtained.

Thus, none of education, employment or narcology registration affect response rate among cases or controls, but are associated with different response rate in each. (i.e. distribution of these variables is similar among those cases who did and did not provide validation interview and the same among the controls, but the two distributions differ from one another). Conversely, age does appear to affect response rate whereby response rates are higher among both cases and controls in the older age groups, and the youngest age group. However, overall the absence of major differences in these results support the assumption that analyses performed on this subset of households for which a validation interview was successfully obtained may be generalised to the larger dataset

Having established that the distribution of index characteristics did not substantially differ between households in which a validation interview was/was not obtained, an investigation was carried out to explore whether there were substantial differences in the pattern of proxy1 responses in these groups that could limit generalisability.

**Table 8.9** *Distribution of index characteristics among case/control households in which a second proxy interview was/was not obtained*

	Case households				Control households			
	Validation interview n	%	No validation interview n	%	Validation interview n	%	No validation interview n	%
<b>Age group of index</b>								
25-29	25	12.5%	11	6.9%	15	7.5%	19	7.0%
30-34	12	6.0%	17	10.6%	9	4.5%	29	10.6%
35-39	10	5.0%	23	14.4%	7	3.5%	43	15.8%
40-44	26	13.0%	32	20.0%	26	13.0%	51	18.7%
45-49	53	26.5%	34	21.3%	57	28.5%	66	24.2%
50-54	74	37.0%	43	26.9%	86	43.0%	65	23.8%
<b>Educational level of index</b>								
some/complete secondary	91	45.5%	63	39.4%	68	34.0%	88	32.2%
professional school	59	29.5%	50	31.3%	46	23.0%	41	15.0%
specialised secondary	30	15.0%	32	20.0%	49	24.5%	67	24.5%
some/complete higher	17	8.5%	13	8.1%	35	17.5%	74	27.1%
missing	3	1.5%	2	1.3%	2	1.0%	3	1.1%
<b>Employment status of index</b>								
regular paid employment	89	44.5%	75	46.9%	167	83.5%	235	86.1%
unemployed for other reasons	56	28.0%	45	28.1%	22	11.0%	24	8.8%
unemployed due to invalidity	48	24.0%	36	22.5%	9	4.5%	12	4.4%
unemployed due to ill health	7	3.5%	4	2.5%	2	1.0%	2	0.7%
<b>Registration at narcology service (index)</b>								
no	170	85.0%	140	87.5%	194	97.0%	262	96.0%
yes	30	15.0%	20	12.5%	6	3.0%	11	4.0%
<b>Total</b>	<b>200</b>	<b>100.0%</b>	<b>160</b>	<b>100.0%</b>	<b>200</b>	<b>100.0%</b>	<b>273</b>	<b>100.0%</b>



### *Representativeness of households in which a validation interview was obtained: formal evaluation*

In order to explore whether the pattern of proxy1 responses relative to the index response differed in the subset analysed in this chapter, an investigation of agreement between the index and proxy1 was carried out, comparing households in which a validation interview was obtained with households for which this was not the case. Agresti's loglinear model was used to formally investigate the difference in agreement between the control and proxy1 in these two groups.

### *Alcohol related questions*

Table 8.10 displays  $\tau$  coefficients for this difference, along with their p-value for the null hypothesis that there is no difference in agreement between pairs for the range of questions relating to alcohol use. Exactly one third of the questions examined have a  $\tau$  which lies below 0 (no difference between groups), so although a binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number is non-significant, there is a very slight tendency for the index-proxy agreement in those households which produced a validation interview to be weaker than those which did not. Examination of the range of values obtained for  $\tau$  reveals that the magnitude of any difference is small: most of the values fall close to a null result of 0, with only a few results of any interest. Notably, question L16 ('Does he ever drink large quantities of spirits without also eating some food?') has a  $\tau$  slightly larger than most other values, indicating that those included in the subset examined may report this question more differently to the index than those excluded. Question L25 ('Has he been on zaponi in the past year?') also has a relatively large  $\tau$ , indicating the opposite – that this question is better reported by those in this subset than in the overall dataset, although this difference is not statistically significant. Only three of the 30 questions examined here show statistical evidence of a difference at the 5% level, and after application of a Bonferroni correction, no test is statistically significant when using a corrected critical p value of 0.002. Overall, there are no questions for which the difference which statistically differs from a null value of 0, indicating that for alcohol questions, the subset analysed within this chapter can be considered to be representative of the whole dataset.

**Table 8.10**  $\tau$  and  $p$ -value for the difference in index-proxy1 agreement for questions relating to alcohol use in households for which a validation interview was not/was obtained

Question	$\tau$	$p$ value
L1 How often is beer usually drunk?	0.21	0.56
L2 How often is wine usually drunk?	-0.26	0.58
L3 How often are spirits usually drunk?	0.42	0.25
L4 How often are other alcoholic substances drunk?	0.37	0.92
L5 On which day is beer usually drunk?	0.73	0.11
L6 On which day is wine usually drunk?	0.19	0.70
L7 On which day are spirits usually drunk?	0.08	0.86
L8 On which day are other alcoholic substances usually drunk?	0.38	0.80
L9 How much beer is usually drunk on one occasion?	0.14	0.73
L10 How much wine is usually drunk on one occasion?	-0.30	0.56
L11 What quantity of spirits is usually drunk on one occasion?	-0.19	0.68
L12 What is the maximum quantity of beer ever drunk on one occasion?	0.02	0.96
L13 What is the maximum quantity of wine ever drunk on one occasion?	0.04	0.94
L14 What are the maximum quantity of spirits ever drunk on one occasion?	0.27	0.51
L15 Does he ever drink spirits together with either beer or wine at the same sitting?	0.09	0.82
L16 Does he ever drink large quantities of spirits without also eating some food?	1.98	0.01
L17 How often does he become excessively drunk?	-0.19	0.67
L18 Does he ever drink alcohol before noon?	-0.12	0.79
L19 How often does he have a hangover?	-0.66	0.15
L20 How often does he fail to fulfil his work obligations due to drinking alcohol?	-0.85	0.35
L21 How often does he fail to fulfil his family or personal obligations due to drinking alcohol?	0.64	0.33
L22 Does he ever go to sleep at night without taking his clothes off because of being drunk?	-0.77	0.32



Question		$\tau$	p value
L23	Does he ever drink alone?	0.81	0.03
L24	Does he usually drink alcohol at home or in other places?	0.76	0.03
L25	Has he had one or more episodes of zepoi in the past year?	-1.18	0.20
L32	Has he been arrested because of being drunk during the past year?	0.20	0.82
L33	Does he currently drink more, less or about the same as one year ago?	0.52	0.18
L34	Does he currently drink more, less or the same as one month ago?	0.19	0.63
L36	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?	-0.58	0.46
L38	Has he ever been taken to a sobering up centre?	0.17	0.70

### *Tobacco use, socioeconomic factors and health related questions*

Table 8.11 displays the results of a similar analysis exploring the difference in agreement between the control and proxy1 for households in which a validation interview was/was not conducted for questions on smoking, socioeconomic factors and aspects of health.

A binomial test of the null hypothesis that the proportion of negative  $\tau$  values is half the total number is statistically significant, with the confidence interval falling well below the expected mean of 0.5. Examination of the range of values obtained for  $\tau$  in this table reveals that almost every value is positive, indicating a slight tendency for first proxies not in households in which a validation interview was conducted to agree more closely with the control. However, only a small number of questions display  $\tau$  values which are statistically different to 0 at the 5% level, and applying a Bonferroni correction to this table leaves only one question, M6, statistically significant based on a corrected critical p value of 0.004 (0.05/14). These results continue to support the assumption that this subset is representative of the wider dataset with respect to questions on smoking, socioeconomic factors and health.

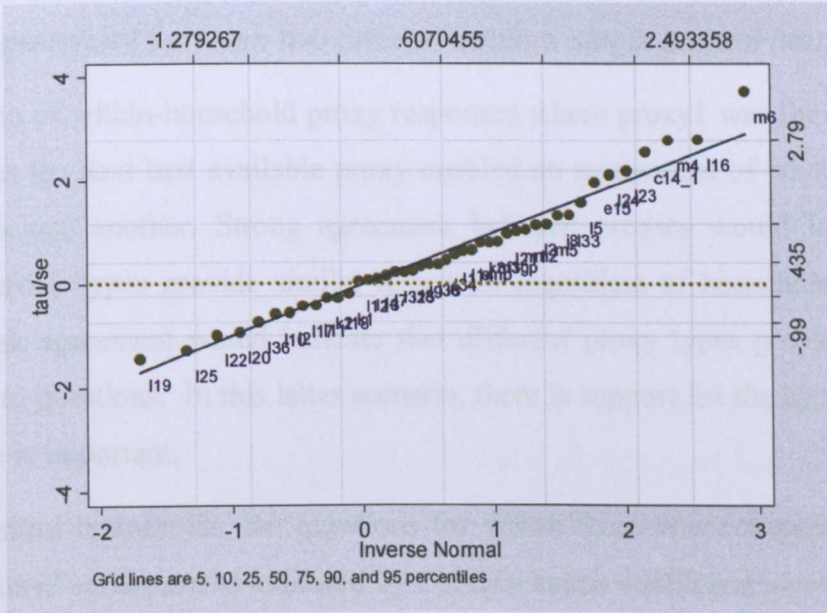
*Table 8.11  $\tau$  and p-value for the difference in index-proxy agreement in control households for which a validation interview was not/was obtained for questions relating to tobacco use, socioeconomic factors and aspects of health*

Question	$\tau$	p value
M1 Is he a current smoker?	1.28	0.30
M2 How many years ago did he stop smoking regularly?	1.84	0.29
M3 What does he smoke most often?	0.83	0.42
M4 When he smoked, how many per day was usual?	1.31	0.01
M5 How old was he when he started smoking regularly?	0.58	0.25
M6 Have his parents ever smoked?	3.43	0.00
E15 What is his marital status?	2.91	0.05
F3 Is he in regular paid employment?	0.64	0.50
C14 Does his household own a car?	1.24	0.01
J8 Is he registered disabled?	3.78	0.18
F1 What is his level of education?	0.46	0.41
K1 Has he had any broken bones in the past year?	-0.21	0.84
K2 Does he usually cough in the morning?	-0.13	0.78
K3 In the past few months, could he climb up a flight up of stairs without becoming breathless?	0.52	0.42

Considering all these questions together, a quantile-quantile plot shows that the questions are normally distributed about a mean which lies just above 0 (0.61, 95% CI 0.26, 0.96). This indicates a slight tendency for those included in the subset to have slightly poorer index-proxy agreement than the wider dataset. However, the absence of important outliers, and the slight magnitude of the shift in agreement supports the generalisability of results obtained in this chapter.



Figure 8.4 Quantile-quantile plot of  $\tau$ /standard error for the difference in index-proxy agreement in pairs of respondents in control households for which a validation interview was not/was obtained



### 8.4 Discussion

In Chapter 7 it emerged that, in line with the literature, spouses appear to provide the most valid responses to a range of questions with respect to the index. It is plausible that these findings are confounded by properties of the household from which respondents and indexes come: the setting in which indexes and their proxies live undoubtedly affects the type of proxy available, and this setting may also affect and be directly responsible for aspects of index behaviour and the quality of index-proxy relationships which influence the level of agreement between index and proxy responses.

This chapter explored the issue of whether certain properties of the household – known or unknown – are to some extent responsible for the apparent differential validity of proxy responses according to the index-proxy relationship. In other words, does proxy type make a difference *per se* to the validity of proxy responses, or does the household confound the findings of Chapter 7. In exploring the agreement between two within-household proxies, there was automatic adjustment for

properties of the household which may impact on the apparent validity of proxy responses, and it was therefore possible to further untangle the factors driving validity of proxy response with respect to proxy type.

*Is there agreement between two proxies within a single control household?*

Comparison of within-household proxy responses where proxy1 was the spouse and proxy2 was the next best available proxy enabled an assessment of whether proxies agree with one another. Strong agreement between proxies would indicate that different proxy types provide similar responses regardless of household attributes, whilst weak agreement would indicate that different proxy types provide different responses to questions. In this latter scenario, there is support for the hypothesis that proxy type is important.

Within control households, the questions for which there was comparatively poor proxy1-proxy2 agreement as indicated by Cohen's kappa coefficient were few. These questions tended to ask about aspects of the index's behaviour which are arguably difficult for a proxy to be easily able to observe due to the necessity for detailed knowledge (e.g. 'When he smoked, how many per day was usual?') or knowledge of behaviours occurring away from the home (e.g. 'Does he usually drink alcohol at home or in other places?'). In fact, there was considerable overlap between these questions and the questions identified in Chapter 7 as eliciting poor index-proxy agreement in general. It is plausible that proxies are unable to provide valid responses to these questions regardless of their relationship to the index, and the misclassification may be either random or directional according to specific proxy type, but is universally present, resulting in low agreement between proxies in control households.

*Are spouses more valid than other proxy respondents?*

By examination of index-proxy agreement using two different proxies within the same households it was possible to draw conclusions regarding the effect of whether a proxy is the spouse versus the next best available respondent on agreement with the index. In line with the general finding that, to some extent, within-household proxies agree with each other, the analyses conducted in this chapter did not reveal spouses

to be better informants than the next available proxy. There was very little detectable statistical difference in the agreement between controls and proxy1 versus controls and proxy2, indicating that although proxies may not agree strongly with one another, they are equally invalid with respect to the index in control households.

This is a novel finding, and suggests that proxy type may be less important than previously deduced in driving validity of proxy responses. Instead, it is attributes of the household and/or the index which result in proxies being more or less valid at informing about the index. Considered along with the findings of Chapter 7 which indicated that spouses tend to be in slightly better agreement with the index than other types of proxy, there is a suggestion that one such attribute is the fact that the index has a spouse at all. It may be that men who have a spouse, compared with men who have never had a spouse or who have lost their spouse, tend toward behaviours which are less difficult for their proxies to report accurately and consistently.

#### *Do these findings differ in case versus control households?*

Another such attribute is the fact of death of the index, which could be anticipated to affect the responses provided by different members of the household. The responses provided by two proxies within case households could not, of course, be compared to the case, therefore the analyses carried out in control households could not be replicated. However, an analysis comparing the within-proxy agreement in case compared with control households provided some evidence regarding whether agreement differs according to case/control status, *i.e.* the fact of death.

So is there any case-control bias in the importance of proxy type? Although examination of Cohen's kappa coefficients at the beginning of this chapter appeared to indicate that case proxies tend to agree more closely with one another than control proxies for this range of questions, when using Agresti's loglinear model little support for this was observed. In a formal comparison of agreement between pairs in the two types of household, there was little detectable difference in agreement beyond that expected by chance.

However, the indication of stronger concordance between case proxies cannot be ignored. Despite the lack of a statistically detectable difference, it does appear that choice of proxy may have a lesser impact on the validity of proxy response in case

compared with control households. It is important to note that this finding pertains to the *relative*, not *absolute* validity of these responses, but in the absence of a case (index) to interview, it is not possible to identify which type of proxy is most valid for any given question in case households.

The reasons behind this finding can be speculated upon. It is plausible that the fact of the recent death of the index encourages proxies within any given household to uniformly under-, or indeed over- estimate the behaviours in question. It is also likely, however, that the fact of death is related to the behaviours in question, and that cases in this study tend towards heavier drinking behaviours. The nature of such behaviours would be more apparent to proxies, making these specific questions less difficult to validly answer for any proxy. This would have the result of greater uniformity in proxy responses in case households. Thus, despite the apparent case-control bias in the importance of proxy choice, whereby the selection of proxy has a greater impact on the validity of findings among controls than among cases, it may be behaviours related to the fact of death, rather than the fact of death itself, which are the overriding factors influencing proxy responses to these questions.

### *Limitations*

The analyses presented in this thesis are carried out using proxies selected according to a protocol designed to ensure that the proxy has good knowledge of the index. The extent to which differences in proxy validity can be detected is therefore limited, since all proxies have been selected on the basis of being expected to provide reasonably valid responses. The weakness of some of the findings here may be attributable, in part, to this limitation of these data, and the strength of findings could plausibly increase where such a stringent screening protocol was not applied.

A further limitation of the analyses presented in this chapter is that they were conducted using relatively small sample sizes, and it is plausible that this has led to the false negative results which contrast with the findings of Chapter 7. Repetition of these analyses with a larger study population could result in amplification of slight positive effects of proxy type which have not convincingly emerged here.



### *Concluding comments*

Consideration of the evidence presented in this chapter does suggest that proxy type may be less important than previously suspected in terms of agreement with an index. Instead of specific attributes of the proxy *per se* driving differences observed in previous analyses, it appears that it is attributes of the index or households which are, in fact, influencing the validity of the proxy responses. Such attributes will include many unmeasured characteristics of the index, the proxy and the household, but two emerge here as particularly important. There are firstly, whether the index has a spouse (rather than whether the proxy is the spouse), and secondly, the fact of death itself. Whilst this latter attribute cannot be controlled – it is an integral weakness of this type of case control study – it is reassuring that the difference observed here is modest. However, the former finding has implications in terms of choice of index in this type of study. Whilst more valid data may be collected if subjects are limited to those who have spouses, the generalisability of such research would also be limited to men who have spouses. In the light of the magnitude of the difference in agreement observed, this trade-off in proxy validity against generalisability of findings must be carefully considered in the design of any study which uses proxy respondents.

## **Chapter 9 Impact of using proxy data on case-control results**

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In this chapter, the focus turns to what is arguably the most important issue associated with using proxy respondents in place of index respondents to collect questionnaire data: the impact on study findings. In previous chapters there has been much focus on validity of proxy respondents at an individual level. Findings have been interesting and informative regarding effects of characteristics of the index, of the proxy and of the index-proxy relationship on the validity of proxy responses. However, in this chapter we return to the motivation behind these exploratory analyses and address an important question: what difference, if any, does the use of proxy respondents make to the findings of a case-control study?

### **9.1 Summary of chapter contents**

This chapter begins by assessing what impact there is on measures of effect obtained in a case-control study examining the effect of alcohol on all-cause mortality when the best available proxy is used, rather than self-reported data. There is then an investigation of the effect of using proxies defined by particular attributes of the index-proxy relationship. Firstly, analyses explore the impact of the use of spouses rather than self-reported data, and secondly, the impact of the use of proxies who report 'good' or 'extremely good' knowledge of the index, rather than self-reported data.

### **9.2 Methods**

Odds ratios obtained in a case-control setting – at least in a univariate situation - are a reflection of aggregate, marginal distributions. Whilst high levels of agreement between control and control proxy responses will probably mean that two ORs obtained using data from these two different sources will be very similar, lower levels of agreement does not necessarily lead to dissimilar ORs. Therefore, examination of individual-level agreement only is not sufficiently informative regarding whether use of proxy responses has a substantial impact on measures of

effect obtained. Here, a comparison of odds ratios obtained when using different respondents will be made in the context of a large case-control study.

The Izhevsk Family Study is a case-control study whose central hypothesis focused on the risk factors of premature mortality among Russian men of working age (25-54), concentrating on alcohol use as the primary exposure. The study design and methods are described in detail in Chapter 3. Using this unique dataset comprising proxy data for case and controls, as well as interview data with the controls themselves, it is possible to investigate the question of the impact of using proxy data on study findings.

Firstly, the question of whether the use of proxies has any impact on measures of effect obtained: whether ORs are changed, and in which direction. Secondly, whether the use of spouses, identified in previous chapters as likely to be the most valid respondents compared with self-report, has any impact on measures of effect. Finally, whether the use of proxy reports from individuals who report 'good' or 'extremely good' knowledge of the index, versus self-reports of control exposures in the same households has any impact. Other subsets explored in previous chapters did not show any evidence of improving proxy validity, and therefore will not be explored further in this chapter. The intention here is not to estimate the true association between alcohol consumption and mortality in this case control study, since further elaboration of the analyses would be necessary to address this. Rather, the aim is to compare the mortality adjusted odds ratios obtained using different respondents as detailed below.

Logistic regression was used to obtain all-cause mortality odds ratios according to different types of alcohol consumption (frequency of beer, wine, spirits, surrogates consumption), adjusted for age, smoking status and some socioeconomic factors. The analysis was repeated using the following restricted subsets of households:

- All households included in previous analyses: case proxy versus control proxy data, case proxy versus self-reported control data
- Restriction to households where proxy 1 was the index's spouse: case proxy versus control proxy data, case proxy versus self-reported control data

- Restriction to households where proxy 1 reported ‘good’ or ‘extremely good’ knowledge of the index: case proxy versus control proxy data, case proxy versus self-reported control data

In order to avoid confounding by attributes of the control household, self-reported control data and control data were included in each analysis on a household basis: i.e. self-reported data was examined only if the control’s proxy met the above criteria. The small number of questionnaire items within these samples with missing data, however, were not excluded (Appendix 8).

### *Variables*

The outcome explored was all-cause mortality. Primary exposures comprised a range of variables relating to alcohol use, specifically - frequency of consumption of beer (L1), wine (L2), spirits (L3) and surrogates (L4) (daily or almost daily, 3-4 times per week, 1-3 times per month, never or almost never). Analyses were adjusted for the following exposures: age group (25-29, 30-34, 35-39, 40-44, 45-49, 50-54), smoking status (M1) (current, ex-smoker, never-smoker), education (F1) (some/complete secondary, professional, specialized secondary, some/complete higher), employment (F3) (regular paid employment, unemployed due to disability, unemployed due to ill health, unemployed – other), marital status (E15) (living together with spouse in a registered marriage, living together with spouse but not in a registered marriage, divorced/separated, widowed, never married), household ownership of a car (C14) (yes, no).

## 9.3 Results

By comparing the odds ratios obtained when using specific proxies as respondents for control data, as compared with the control self-reports, it is possible to evaluate the impact of using proxy reports on study outcomes in a case control study.

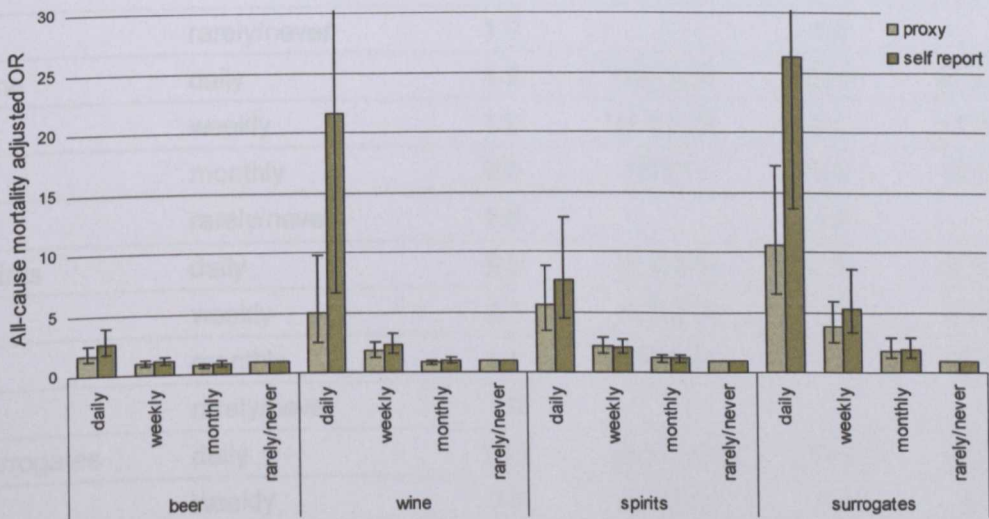
The distribution of observations by respondent type for each subset examined is presented in Appendix 8.

### 9.3.1 Comparison of odds ratios obtained in all households

Figure 9.1 and Table 9.1 show the mortality adjusted odds ratios by frequency of drinking in all households, displaying results obtained using proxy data for controls alongside those obtained when using self-reported data.

It is clear that the general impact of using proxies is to underestimate the mortality adjusted OR relative to that obtained using self-reported data, and that the magnitude of underestimation varies substantially by alcohol type and frequency category.

Figure 9.1 Mortality adjusted odds ratios and 95% confidence interval by frequency of drinking in all households



Reference category: rarely/never for all exposures.

ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership

The impact is modest or absent for the categories representing monthly or weekly consumption for all types of alcoholic drink examined. However, as the alcohol consumption category becomes more extreme, so does the difference in estimated OR with the greatest differences observed for daily consumption of all drinks. In particular, the difference in observed OR for the effect of daily surrogate consumption is large, although there is overlap in confidence intervals, and the point estimate for daily consumption of wine is also large, although examination of the confidence intervals for this type of beverage again indicates that these estimates are imprecise due to the small sample sizes in the categories examined, and therefore cannot be interpreted with confidence. This scenario, in which fewest restrictions are made to the households included, results in the largest sample size and is perhaps the most useful of the three examined in this chapter in a real setting. Therefore these results are of particular interest.

**Table 9.1** *Mortality adjusted odds ratios by frequency of drinking in all households*

		Proxy-reported data		Self-reported data	
		OR	95% CI	OR	95% CI
beer	daily	1.7	(1.2,2.4)	2.6	(1.8,3.9)
	weekly	0.9	(0.7,1.2)	1.1	(0.9,1.4)
	monthly	0.7	(0.5,0.9)	0.8	(0.6,1)
	rarely/never	1.0	-	1.0	-
wine	daily	4.9	(2.5,9.8)	21.5	(6.5,70.8)
	weekly	1.7	(1.2,2.5)	2.2	(1.5,3.2)
	monthly	0.8	(0.6,1)	0.9	(0.7,1.1)
	rarely/never	1.0	-	1.0	-
spirits	daily	5.5	(3.4,8.8)	7.6	(4.5,12.8)
	weekly	2.1	(1.6,2.8)	2	(1.5,2.7)
	monthly	1.1	(0.9,1.5)	1.1	(0.9,1.5)
	rarely/never	1.0	-	1.0	-
surrogates	daily	10.6	(6.5,17.2)	26.2	(13.5,51)
	weekly	3.8	(2.5,5.9)	5.3	(3.3,8.6)
	monthly	1.8	(1.2,2.8)	1.8	(1.2,2.9)
	rarely/never	1.0	-	1.0	-

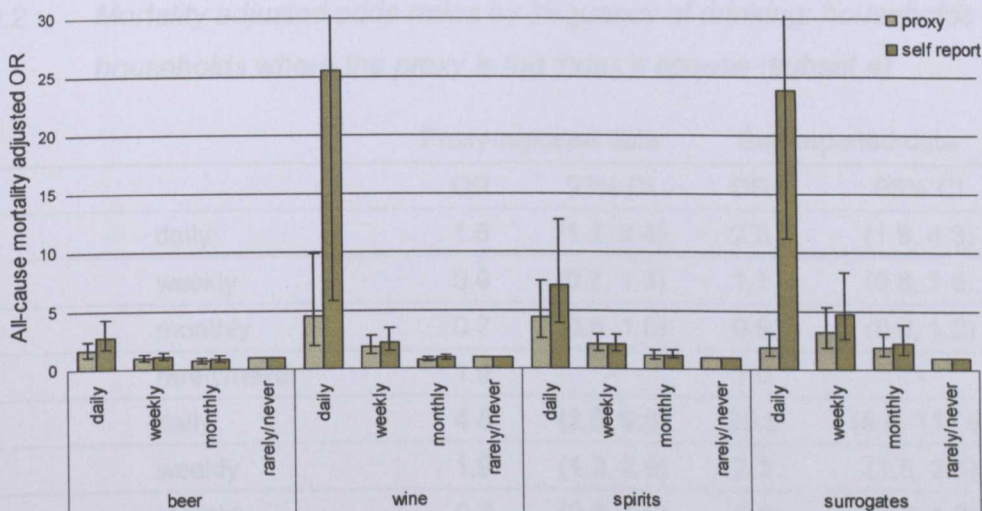
*ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership*



### 9.3.2 Comparison of odds ratios obtained in households where the proxy is the index's spouse (subset 4)

As previously discussed, the spouse is widely held as the preferred choice of proxy respondent according to the literature (Chapter 1), and previous analyses in this thesis suggest that spouses may be the most valid proxy respondents. Figure 9.2 and Table 9.2 show the mortality adjusted odds ratios by frequency of drinking in household for which the proxy is the index's spouse, displaying results obtained using proxy data for controls alongside those obtained when using self-reported data.

Figure 9.2 Mortality adjusted odds ratios and 95% confidence intervals by frequency of drinking in households where the proxy is the index's spouse (subset 4)



Reference category: rarely/never for all exposures

ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership

It is clear that the general impact of using spouses as proxies rather than self-reported data is again to consistently underestimate the mortality adjusted OR. The overall trend is consistent with the result observed when using the whole dataset, whereby there is very little difference in the estimated effect of infrequent drinking of any type of alcohol, but as the alcohol consumption category becomes more extreme, so

does the difference in estimated OR with the greatest differences observed for daily consumption of all drinks, and in particular, daily consumption of surrogates.

It is not surprising that examination of the adjusted mortality odds ratios obtained using index versus proxy data in households where the proxy is the index's spouse demonstrates similar patterns to the previous analysis, since this group of respondents comprises the a large proportion of the whole sample (86% among control households, 60% among case households). However, the findings are not identical: when only households for which the proxy is the index's spouse are included, the magnitude of the difference in OR obtained using proxy and index control data is intensified. Most strikingly, the OR for daily surrogates consumption is greatly and significantly underestimated when using proxy-reported data compared with self-reported data in this sample.

**Table 9.2** *Mortality adjusted odds ratios by frequency of drinking: households in households where the proxy is the index's spouse (subset 4)*

		Proxy-reported data		Self-reported data	
		OR	95% CI	OR	95% CI
<b>beer</b>	daily	1.6	(1.1, 2.4)	2.8	(1.8, 4.3)
	weekly	0.9	(0.7, 1.3)	1.1	(0.8, 1.5)
	monthly	0.7	(0.5, 1.0)	0.9	(0.6, 1.2)
	rarely/never	1.0	-	1.0	-
<b>wine</b>	daily	4.5	(2.0, 9.8)	25.5	(5.8, 111.6)
	weekly	1.9	(1.3, 2.9)	2.3	(1.5, 3.5)
	monthly	0.7	(0.6, 1.0)	0.9	(0.7, 1.2)
	rarely/never	1.0	-	1.0	-
<b>spirits</b>	daily	4.4	(2.6, 7.5)	7.1	(3.9, 12.8)
	weekly	2.1	(1.5, 3.0)	2.2	(1.5, 3.0)
	monthly	1.2	(0.9, 1.6)	1.2	(0.9, 1.7)
	rarely/never	1.0	-	1.0	-
<b>surrogates</b>	daily	1.9	(1.1, 3.1)	23.8	(11.2, 50.6)
	weekly	3.2	(1.9, 5.3)	4.7	(2.7, 8.3)
	monthly	1.9	(1.1, 3.1)	2.3	(1.4, 3.8)
	rarely/never	1.0	-	1.0	-

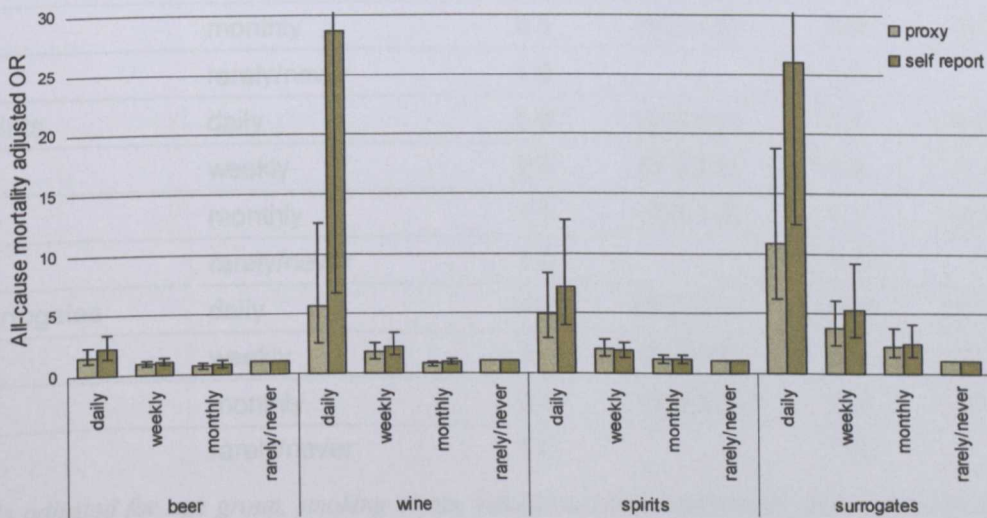
*ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership*



9.3.3 Comparison of odds ratios obtained in households where proxies report 'good' or 'extremely good' knowledge of the index (subset 2)

Examining the ORs obtained using data from those households within which the proxy reported 'very good' or 'extremely good' knowledge of the index, an overall tendency is once again observed for estimates obtained using proxy data to be more conservative than those obtained using self-reported data (Figure 9.3 and Table 9.3). Notably, confidence intervals overlap in every instance, suggesting a lack of statistically significant difference between ORs obtained. However, for some of the larger effects in particular, the difference between point estimates is large and the overlap is at the extremes of the range of possible values, indicating that a difference is plausible. The estimated effect of monthly consumption of different alcoholic beverages or surrogates is again hardly affected by the use of proxy versus self-reported data. The differences in estimates for 'weekly' consumption are slightly larger for wine and surrogates, but not for beer or spirits.

Figure 9.3 Mortality adjusted odds ratios and 95% confidence intervals by frequency of drinking in households where proxies report 'good' or 'extremely good' knowledge of the index (subset 2)



Reference category: rarely/never for all exposures

ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership

Substantially overlapping confidence intervals for these two former alcohols (wine and surrogates) suggests these imprecise estimates may differ by chance, although the lack of a detectable statistical effect does not necessarily indicate lack of a real tendency that would be detected in a larger sample. The estimated OR obtained using proxy and self-report for 'daily' wine and surrogates consumption persist in showing large differences in point estimates, as observed in the previous samples examined. However, the confidence intervals between the two estimates show considerable overlap here for both wine and surrogates, providing less evidence of an extreme effect using these proxies than when using spouses only.

**Table 9.3** *Mortality adjusted odds ratios by frequency of drinking using proxies who report 'good' /'extremely good' knowledge of the index (subset 2)*

		Proxy-reported data		Self-reported data	
		OR	95% CI	OR	95% CI
<b>beer</b>	<b>daily</b>	1.5	(1.0,2.3)	2.2	(1.4,3.4)
	<b>weekly</b>	0.9	(0.7,1.2)	1.1	(0.8,1.4)
	<b>monthly</b>	0.7	(0.5,0.9)	0.8	(0.6,1.1)
	<b>rarely/never</b>	1.0	-	1.0	-
<b>wine</b>	<b>daily</b>	5.7	(2.6,12.5)	28.6	(6.7,121.2)
	<b>weekly</b>	1.7	(1.1,2.5)	2.2	(1.5,3.3)
	<b>monthly</b>	0.8	(0.6,1.0)	0.9	(0.7,1.2)
	<b>rarely/never</b>	1.0	-	1.0	-
<b>spirits</b>	<b>daily</b>	5.0	(2.9,8.4)	7.1	(4.0,12.8)
	<b>weekly</b>	2.0	(1.5,2.8)	1.8	(1.3,2.5)
	<b>monthly</b>	1.1	(0.8,1.5)	1.1	(0.9,1.5)
	<b>rarely/never</b>	1.0	-	1.0	-
<b>surrogates</b>	<b>daily</b>	10.8	(6.2,18.7)	26.0	(12.4,54.6)
	<b>weekly</b>	3.7	(2.3,6.1)	5.3	(3.1,9.1)
	<b>monthly</b>	2.3	(1.4,3.8)	2.4	(1.5,4.1)
	<b>rarely/never</b>	1.0	-	1.0	-

*ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership*

## 9.4 Discussion

In this chapter, an evaluation of the impact of the use of proxies in a case control study of premature mortality was conducted. Having demonstrated that proxies provide reasonably valid responses to certain classes of question, and that spouses may be more valid respondents than other proxy types, it was of particular interest to investigate the consequences of these findings by addressing two questions: firstly, does it make any difference to measures of effect obtained by a case-control study of examining the effect of alcohol consumption on mortality if proxy data is used instead of self-reports? and secondly, does restricting to those specific proxy types expected to provide more valid data have any further impact?

### *Does the use of proxy-reported data make any difference to study findings?*

The odds ratios obtained using self-reported data tended to be inflated relative to those obtained using proxy-reported data, especially in the most extreme response categories and for surrogate and wine consumption. This reflects the tendency for controls to underestimate their own alcohol consumption relative to their proxies. This is in accordance with the findings of Chapter 7 which assessed index-proxy agreement for a range of questions about alcohol consumption as well as other exposures.

A case-control study exploring alcohol-related determinants of mortality using proxy respondents for controls draws more *conservative* conclusions than using index respondents. The practical implications of this are interesting: the use of proxy respondents does not appear to result in an overestimation of effect when exploring alcohol consumption as a primary exposure of mortality. However, it is important to note that although the estimate of this context-specific main effect measure errs in the direction of conservatism, if these data were used to estimate population prevalences of alcohol consumption, the result would be a substantial overestimate, and the use of proxy responses about exposures for which the proxy underestimated with respect to the index would result in a relative over-estimate of the measure of effect.

### *The impact of systematic and random misclassification of responses*

All respondents are supplying answers to questions which are attempting to measure an actual underlying behaviour. There is almost certainly random and non-random misclassification with respect to this behaviour among all types of respondent which will have affected the measures of effect obtained.

Initially considering controls and their proxies, it is not possible to confidently deduce which type of respondent tends to report most accurately with respect to this underlying behaviour. However, results from Chapter 7 and those presented in this chapter indicate that, apart from a few exceptions, there is a general tendency for control proxies to report systematically higher alcohol consumption than the controls themselves. This suggests that for either proxies, indexes or both, there is non-random misclassification relative to the actual underlying behaviour. It cannot be ruled out that proxies are reporting more accurately with respect to this underlying behaviour, and the indexes are underestimating. In this scenario, the OR obtained when using proxy respondents are closer in magnitude to the real – unknown – value and the ORs obtained using index data are overestimates. The converse may also be true, i.e. proxies may be systematically overestimating alcohol consumption relative to valid self-reports, in which case the ORs obtained when using proxy respondents are an underestimate of the real value and those obtained using index data are more valid.

Misclassification among case proxies is also relevant in consideration of the impact on measures of effect obtained. If the extent of systematic misclassification among case proxies is similar to that among control proxies, then the overall measure of effect will be valid, despite invalid prevalence estimates within each group. If the magnitude of systematic misclassification tends towards greater over-reporting of alcohol consumption among case proxies than control proxies, then the resulting OR will be increased. If the magnitude of misclassification is less among case proxies, the OR will be diminished. It is also conceivable that case proxies and control proxies systematically misclassify in opposite directions, in which case the resulting measure of effect would be more dramatically attenuated (if control proxies over-report and case proxies under-report) or increased (the opposite situation). In the

absence of an index against which to compare case proxy reports, it is not possible to ascertain the extent or direction of systematic misclassification among case proxies.

Finally, random misclassification is likely to occur to some extent among all types of respondent, in particular where index-proxy agreement is weak and no general tendency is observed in terms of control proxies over- or under-reporting relative to indexes. This will have had the effect of attenuating the ORs obtained.

*Is there any further effect when restricting to proxies of specific types?*

There is little statistical evidence to suggest that the absolute magnitude of odds ratios obtained using proxy-reported data is affected by restriction to the subsets which contain proxies who should be better able to validly report with respect to the index (those in which the proxy is the index's spouse; those in which the proxy reports 'very good' or 'extremely good' knowledge of the index). There is, however, a tendency for slight attenuation of effects when restricting to households in which the proxy is the spouse, and a tendency for a decrease in precision.

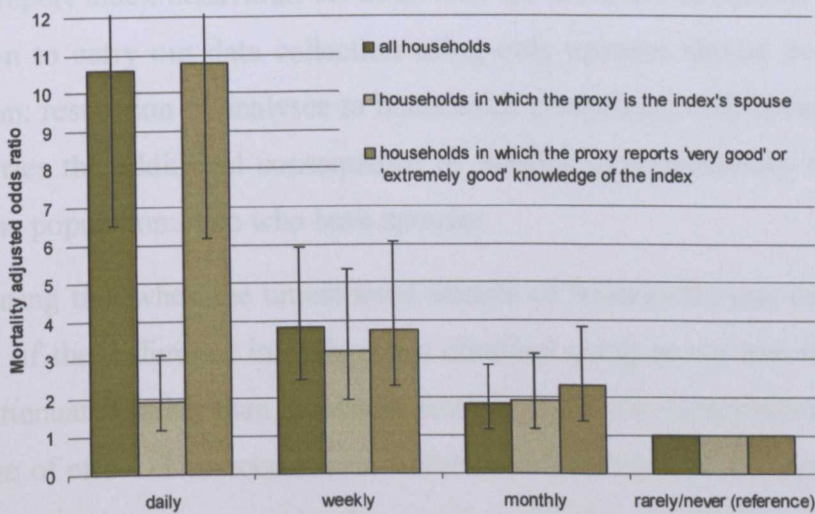
The fact that the estimated odds ratios observed when using self-reported data are higher when using the restricted samples than when considering all households supports the previous supposition that there may be an intrinsic difference in the behaviour of indexes in those households where there is a spouse. The behaviour of these indexes would plausibly be less extreme in terms of alcohol consumption, which would lead to decreased precision in the estimates due to exclusion of many of the most extreme observations, which is indeed observed in the wider confidence intervals for subset 4 (spouses only). Additionally, however, if the tendency for indexes whose proxy is not their spouse to have more extreme behaviour is particularly true of cases, this would result in a weaker association between alcohol consumption and mortality. In other words, these findings are not only reflective of the extent to which proxies under-report index alcohol consumption, but also of the fact that index behaviour among men who have, for example, a spouse may be more moderate than men who do not.

The hypothesis that men with spouses behave in less extreme ways than men without spouses is supported by examination of the pattern of surrogate consumption, whereby there is a strong association between daily consumption and marital status



(18% of cases with a spouse as proxy reported to drink surrogates daily compared with 30% of cases without a spouse as proxy; 1% of controls with a spouse as proxy reported to drink surrogates daily compared with 4% of controls without a spouse as proxy). By restricting to households in which there is a spouse, the heaviest drinkers (i.e. the group most at risk) among cases (and controls) are excluded. Whilst it is therefore tempting to draw conclusions about the advantages of using spouses as proxies, the above explanation makes the above findings difficult to interpret: the attenuated odds ratios may simply be the result of the association between drinking behaviour and marital status. This is illustrated by comparison of the measures of effect obtained for surrogate consumption when using proxy respondents in the three types of household examined. The effect of daily surrogate consumption collapses when using proxy data from households where the proxy is the spouse, compared with other types of household (Figure 9.4).

**Figure 9.4** Mortality adjusted odds ratios and 95% confidence intervals for frequency of surrogate drinking in different types of household



*Reference category: rarely/never for all exposures*

*ORs adjusted for age group, smoking status, education level, employment status, marital status, car ownership*

### *Concluding comments*

The general tendency observed when carrying out these analyses was for odds ratios to follow similar trends whether obtained using control or control proxy data, and whether examining households in which spouses were proxies, where proxies reported 'very good' or 'extremely good' knowledge of the index, or all households in this dataset. Despite some clear differences in point estimates observed for mortality adjusted odds ratios when comparing proxy- and self-reported data for controls in the same households, large and overlapping confidence intervals mean the actual magnitude of the effect on ORs obtained when using proxies as respondents is unclear, except when examining the most extreme aspects of surrogate consumption.

The diminished differential between ORs obtained using self- versus proxy-reported data in households in which the proxy is the spouse could be interpreted as evidence that, spouses are preferable informants. However, to reiterate earlier discussion regarding this issue, this finding may plausibly be a reflection of characteristics of indexes who have a spouse, rather than any superior ability of the spouse themselves to validly report index behaviour. At odds with the literature consensus (Chapter 1) the decision to carry out data collection using only spouses should be undertaken with caution: restriction of analyses to households comprising only men who have a spouse carries the additional consequence of limiting generalisability to a specific sector of the population: men who have spouses.

It is reassuring that when the unrestricted sample of households was examined, the magnitude of the difference in odds ratios obtained using proxy and index control data was attenuated rather than increased, leading to a more conservative estimate of the measure of effect. This scenario, in which fewest restrictions are made regarding respondent selection, is arguably the most useful for the majority of research situations: it is not always possible to obtain the preferred proxy, and attempting to do so is associated with a reduction in sample size and therefore precision. These results indicate that the inclusion of all proxies actually appears to dilute the extent of differential misclassification of alcohol exposures, resulting in estimates of odds ratios approaching those obtained when using self-reported data. These findings suggest that proxies identified according to a protocol designed to select the best

available proxy may therefore be used with confidence in case control studies examining the effect of alcohol as a primary exposure, and more widely provided care is taken to deduce in which direction estimates will be affected.



## Chapter 10 Discussion

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The overarching motivation of the research presented in this thesis has been to assess whether one can use proxies instead of indexes as a source of valid information about the characteristics and behaviours of index subjects. The empirical work has necessarily been within a specific context: that is a population-based case-control study of premature mortality among men in Russia. Nevertheless a number of important and, in some instances, unexpected findings have emerged that are of general relevance to any epidemiological investigation in which proxies may be used. Extensive comparison of information provided by proxies relative to external data, indexes (in the case of controls) and other proxies has led to the conclusion that in general proxies provide acceptably valid responses to certain classes of question.

The aims of this thesis can be expressed in terms of a number of questions pertaining to the use of proxies in research settings where the index is not available have been addressed. Firstly, does it matter who we ask? *i.e.* are characteristics of the proxy, or attributes of the index-proxy relationship important factors affecting the validity of proxy responses. Secondly, do certain questions elicit better proxy validity than others? Thirdly, what is the validity of proxy-derived data on alcohol consumption and its markers? Finally, what effect does the use of proxy responses in place of index data have on the results of the Izhevsk Family case-control study? These questions are considered in detail in the following discussion.

### *Does it matter who we ask?*

The questionnaire collected proxy-reported information about attributes of the index-proxy relationship. These were whether the index and proxy had cohabited for at least 5 years, whether the proxy had 'very good' or 'extremely good' knowledge of the index, whether there was daily index-proxy contact, and the formal relationship of the proxy to the index, *i.e.* spouse, parent etc. One might expect that proxies who had the most regular, intimate knowledge of indexes would provide the most valid information about their characteristics and behaviour. This was not demonstrated: examination of proxy responses with respect to external data and index data provided little evidence to suggest that this was, in fact, the case. The validity of reporting

being registered disabled or having been in prison by comparison with the relevant external data was hardly affected within either case or control households. One could argue that this particular finding is not surprising, since these are objective and observable measures and therefore comparatively easy for anyone sharing a household with the index to be able to accurately report. However, analyses, presented in Chapter 7, assessing validity of proxies of these different types relative to indexes over a wide range of questions about alcohol-related behaviour, tobacco use, socioeconomic factors and health predominantly failed to indicate any detectable difference.

Of interest, and in contrast with this general result, the finding that spouses may provide more valid responses than other proxies emerged several times in the analyses conducted. This is expected given that an index's spouse would be best informed about his behaviour, characteristics and health compared with other household members, and is consistent with the literature that also suggests that spouses are preferable informants<sup>(5,6,19,29,33)</sup>, as described in Chapter 1.

However, further analyses reported in the thesis (Chapter 8 and Chapter 9) have raised an alternative explanation for this finding. Among households in which an interview was carried out with the spouse, the index *and* the next best available proxy, index-proxy agreement was found to be similar for both proxy types. Although based on relatively small numbers, this apparently contradictory result might be because the behaviours of index subjects in households where a spouse was interviewed might be different to those without a spouse or where the spouse refused to be a proxy. These differences in behaviours may themselves be related to the validity of information collected by any proxy informant regardless of informant type *per se*. Indexes in households where the index has no spouse, either having never married or found a partner, or having lost their spouse through separation or death may have particularly unpredictable behaviours, or be socially or psychologically more isolated, or perhaps evasive, secretive or deceitful in a way that mitigates against valid proxy reporting, particularly of potentially sensitive behaviours such as those, for example, describing or associated with alcohol consumption. In other words, it is attributes of the index (related to whether or not he has a spouse), rather

than attributes of the proxy (*i.e.* whether or not the proxy is the index's spouse) that may contribute to the higher apparent validity of using spouses as proxy informants.

Thus it is suggested that it is attributes of the index, rather than the proxy, that are more important in influencing the validity of proxy responses obtained. Investigation of the most obvious index attribute, the fact of death, provided support for this supposition. Since there was no index data for cases, it was not possible to assess directly how far the agreement of control proxies and controls compared with the agreement between case proxies and cases. Inferences were therefore drawn using two indirect methods. External data provided one possible set of comparative standards, and a second approach was to compare within-household proxy-proxy agreement in case versus control households.

Results indicated firstly that associations between proxy data and external data differed between case and control households. Secondly, there was some evidence to suggest that proxies within case households tended to agree more closely with one another than proxies within control households. These differences in associations are likely to be due, to some extent, to recall bias associated with the fact of death. However, beyond the differences in case-control reporting attributable to such bias, it is likely that these differences are also attributable in part to different underlying behaviours along with the supposition that proxy respondents are able to provide more valid responses to more easily observable questions. Many of the questions asked here relate to exposures associated with mortality, and consequently cases, by definition, tend to exhibit more extreme and, probably, more observable behaviours. Therefore, by comparing case proxies and control proxies, there is a degree of stratification on behaviours which enable proxies to provide more valid responses. For example, for alcohol in particular, cases tended towards heavier use than controls, thereby complicating the interpretation of differences when comparing case and control households for the reasons just described. In other words, it is not the fact of death which is important, but instead, the fact that questions examining mortality-related behaviours are more or less easily classified by proxy respondents according to the case/control status of the index.

In this thesis it has not been possible to separate out these explanations for the differences between case and control reporting of index behaviour. However,

regardless of the driving factors, it is reassuring for the overall research agenda that the magnitude of these differences tended to be small.

*Do certain questions elicit increased validity in proxy responses?*

It is both a strength and a weakness of this research that great efforts were made to design questionnaires that would elicit the most valid proxy responses possible, based on what had been learned from the literature at the inception of the Izhevsk Family Study. Questions were designed to ask about observable characteristics or behaviours, avoid detailed, subjective or sensitive topics, and to be observable by the proxy wherever possible. It is assumed that this has increased proxy validity and benefited the study. However, from the perspective of the sort of methodological investigation conducted in this thesis, this has resulted in a reduced scope for exploration of the effect of style and content of questions on proxy validity. Nonetheless, variability in response validity did arise, and it was possible to make comparisons between the responses elicited by different types of questions.

A range of questions was examined, and variation in the extent of index-proxy agreement was observed. In general, this was easily understandable in terms of the style and form of questions being assessed. Where increased detail or subjectivity was introduced into questions, agreement markedly fell, as expected<sup>(2,6,9,10,14,15,17,22,24,25,27,29,68)</sup>. For example, question L33 ('Does he currently drink more, less or about the same as one year ago?'), L21 ('How often does he fail to fulfil his family or personal obligations due to drinking alcohol?') and L14 ('What is the maximum quantity of spirits ever drunk on one occasion?') consistently elicited low index-proxy agreement and these same questions tended to exhibit poor proxy-proxy agreement in both case and control households where two proxies were interviewed. Conversely, questions which asked about behaviours or characteristics which were easy for the proxy to observe and avoided detailed responses and sensitive subjects, much greater validity was observed. For example, L25 ('Has he had one or more episodes of zapoi in the past year?') and L36 ('Has he ever had help of advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?') had high index-proxy and proxy-proxy agreement, and a range of questions asking about tobacco use and socioeconomic factors elicited particularly

valid responses, for example question M1 ('Is he a current smoker?'), E15 ('What is his marital status?') and F3 ('Is he in regular paid employment?'). These findings support the view that easily-observable, non-subjective behaviours are reported most validly by proxy respondents.

### *What can we learn about alcohol?*

Alcohol use was of particular interest in the Izhevsk Family Study, and was the main focus of the analyses presented in this thesis. Whilst this exposure is of particular interest in the Russian context, it is also of general research interest, included as a main exposure or a confounder in a large number of health- and disease-related studies.

Earlier analyses in this thesis have shown that proxies tend to overestimate alcohol-related behaviour of the index relative to the index himself (Chapter 7). For example, proxies report more frequent index consumption of beer, wine and surrogates (questions L1, L2 and L4), and greater frequency with of the index getting excessively drunk (L17), having a hangover (L19) and drinking alcohol before noon (L18) than the index himself. Given the sensitive nature of alcohol-related exposures in this (and other) context(s), it is most likely that the disagreement arises due to a tendency for self-reports to underestimate actual amount consumed, or frequency of alcohol-related behaviours. For a small number of questions the converse was observed. These questions tended to ask about *quantity* of beverages consumed. It is difficult to speculate why this trend arose. It may be that when questions ask about particularly detailed aspects of behaviour, proxies responses rely on a greater degree of speculation than fact, and in this instance, choose to err on the side of caution in order to portray the index in a favourable light. It is of note, however, that the magnitude of these differences tended to be small and non-significant.

Despite the observed tendency for proxies to over-report alcohol-related behaviours relative to the index, there was little observable difference between index and proxy reports of the question regarding whether the index had received any professional help or advice for an alcohol problem in the past year (L36), and Narcology Dispensary registration. This apparent paradox is clarified to an extent by consideration of the questions concerned. Many of the questionnaire items asking

about alcohol-related behaviours include multiple response categories intended to capture the possible range of index behaviours, permitting substantial variability in responses and, therefore, the possibility of comparative over- or under-estimate by different informants. Conversely, question L36 asks about the occurrence of a defined event (or events), and the response is binary; this provides far more limited scope for variation in responses. Thus, the impact of question form on proxy validity is, once again, suggested.

The factors driving directionality in responses are complex and may plausibly act in either direction: whether the proxy is overestimating the true amount, or the index is underestimating is unclear, and there are well-documented issues associated with using self-report as a gold standard for alcohol questions<sup>(49,50,53,137)</sup>.

*Does the use of proxy respondents affect the results of a case-control study?*

Based on first principles of study design, one would not attempt to conduct a case-control study in which one only collected and analysed proxy data from cases, and index data from controls. Nevertheless, the results presented in Chapter 9 demonstrate the potential scale of the bias in calculated measures of effect arising when comparing such disparate data sources: it is clear that the odds ratios (for alcohol questions) obtained using proxy data for both groups, and proxy data for cases with index data for controls, differ by a considerable amount. This is a reflection of the fact that indexes (controls) reported a lower frequency of alcohol consumption than control proxies. It is not possible to evaluate what the odds ratios for each analysis would be if case *index* data were available. However, it is possible to speculate that, on the basis of the modest magnitude in case/control proxy reporting bias observed in Chapter 8, one might anticipate the odds ratios observed when proxy data are used for both groups to approach those obtained if self-report data were uniformly used. It is, however, an impossibility to evaluate the true extent of bias in retrospective responses obtained from proxies due to the fact of death.

The literature review presented at the beginning of this thesis (Chapter 1) and results of Chapter 6 suggested that spouses may be more valid proxies, and therefore should be preferentially used<sup>(5,6,19,29,33)</sup>. However, as already discussed above, there is an alternative interpretation: it is underlying behaviours of the index, which differ

according to whether they have a spouse, which affect the ease with which proxies are able to observe, and therefore to validly respond to related questions. That is to say, analysis of only those cases and controls who have spouses is effectively research conducted on an altered study population, which comprises men who exhibit less extreme drinking behaviour. This notion is supported by the lower mortality odds ratios obtained when using spouses as proxies, particularly for more extreme categories of alcohol consumption.

### *Strengths and weaknesses*

The analyses conducted in this thesis are based on a study which has considerable strengths in terms of its design and execution. As previously described in detail, the data includes a range of interview data specifically collected with these analyses in mind. The data includes, unusually, interviews with a population sample of controls, as well as the core interviews for control and case proxies. These data were used to examine the quality of data obtained from proxy respondents in an unselected population by comparison with index data. An additional proxy interview was undertaken in a subset of case and control household, allowing evaluation of different types of proxies whilst holding the index and corresponding confounding factors constant. Independent, objective data on Narcology Dispensary registration, Police records and Social Security were also collected, against which proxy and index responses could be compared.

A number of limitations must be considered when addressing the issue of proxy validity using these data. The most obvious and perhaps important limitation is the issue of generalisability: it is essential to keep in mind the setting in which these data were collected and to avoid inappropriate extrapolation of findings. The Izhevsk Family Study was conducted in a specific context: all subjects were residents of a typical, medium sized Russian town on the western side of the Urals, Russia, whose cultural practices and attitudes are not necessarily relevant elsewhere. Most pertinently, the study was primarily concerned with a specific range of exposures - alcohol consumption and associated behaviours - which are particularly extreme in their expression in the Russian context. Average alcohol consumption is believed to be higher in Russia than in most other countries, and cultural attitudes to this and to

the other exposures examined may differ to an extent that affects the validity with which they are reported by any informant. The conclusion to be drawn from this is that an understanding of the perceptions and attitudes to context-specific exposures, and the way in which these affect reporting, is essential in the design of studies incorporating proxy, or index, respondents.

One distinct limiting factor relates to the type of respondents examined. The proxy respondents used in the Izhevsk Family Study were selected based on a protocol which was developed specifically in order to identify what was believed to be the best available proxy from every household. It was therefore not possible to explore the full extent of the effect of proxy type on response validity. Conclusions drawn here about the effect of specific proxy characteristics on validity cannot necessarily be generalised to study settings which do not use the same respondent selection criteria.

A further consideration is the assumption of the validity of self-reports as a comparative standard against which to evaluate the validity of proxy responses. Although index respondents are generally used in preference to proxies when available and, in the light of this convention, this thesis is specifically examining the impact of using proxy reports, it is recognised that self-reports are not necessarily completely valid sources. In the absence of a definitive 'gold standard', there is no way of qualifying this<sup>(49,50)</sup>. In fact, what is known is that validity of self-reports themselves is dependent on a wide range of factors including question content, the interview setting, the respondents themselves, how information is elicited and the interview context<sup>(53)</sup>.

The exclusion of a proportion of interviews was intended to decrease bias affecting the evaluation of validity of proxy responses. However, the resulting decrease in precision is a disadvantage of such exclusions, and further directs generalisability away from a 'real world' setting in which interruptions to interviews, for example, are likely. Conclusions drawn about the impact of using proxy respondents can only be confidently generalised to any study setting comprising the same type of subjects.



### *Concluding comments*

Taking the research agenda forward, it would be useful to investigate the absolute impact of using the protocols employed by the Izhevsk Family study on the validity of proxy responses. The analyses conducted here were not able to evaluate proxy validity for many questions commonly used in observational research: as discussed earlier, questions included in the study were specifically designed with proxy respondents in mind, and therefore the full range of variation in responses according to question content and style was not addressed. Neither were the analyses able to evaluate the use of proxies who did not meet the selection criteria employed in this study. Further research could be conducted to address both these areas. To test and refine the proxy selection protocol employed here is perhaps an unrealistic research agenda, since any study would suffer from deliberate inclusion of proxies judged to provide information that was inferior to that potentially obtainable. However, it would be possible to design a dedicated study to address this issue, which explicitly collected interview data from multiple proxies within households, in sufficient numbers to compare the validity of reporting by spouses compared with other proxy types. Since real life research settings are likely to result in a number of interviews which are interrupted, and it is not always desirable, or possible, to exclude these data, it would also be of particular interest to investigate the validity of responses obtained from interviews which are not conducted according to the protocol employed here.

It would be rash to suggest, based on the evidence here, that households where there is no spouse are not appropriate for proxy-related information gathering, although this is intimated by the tentative findings presented. It appears that spouses are reasonable respondents where exposures are not related to marital status, and may actually be the most valid respondents for some questions. However, restriction to study populations comprising only indexes who have a spouse may be misguided: in particular, where study exposures or outcomes are correlated with marital status, the consequences may be detrimental, as the observed effect will be attenuated by investigation of this restricted study population. The research implications of this are significant: a trade-off in proxy validity against generalisability of findings must be considered in the design of any study which depends upon proxy respondents.

It is recommended that future studies of this type collect external data. Midanik suggests that external data sources are appropriate benchmarks in certain contexts, such as when attempting to validate events such as arrests related to drinking, and hospitalisations<sup>(53)</sup> and these data sources have been used here to demonstrate the validity of proxy responses relative to control (index) responses for a number of questions. Future studies may find it useful to collect such data: even if no explicit methodological objective is addressed, these data provide a persuasive source of information, whether analysed in isolation or in combination with interview data.

In conclusion, it is reasonable for observational studies to use proxies in obtaining data where an index is unavailable at least for most of the exposures considered in this thesis. The analyses here confirm and reinforce some assertions present in the literature regarding proxy validity, and are able to draw specific conclusions regarding the importance of question design and content, the lack of impact of proxy characteristics and the importance of index attributes. With the above caveats in mind, the key message is that it is possible to conduct research with confidence, albeit with caution, when proxies are the only available respondents.

## References

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## **Appendix 1**

### **Fieldwork protocol, proxy respondent selection and respondent information sheet**

## **1.1 Protocol for interviewers: the selection of an appropriate respondent**

Knock on door.

If no answer: return up to 3 times to the same address and begin again with point 1

If someone answers the door: go to point 2

Say: 'I am a researcher from the Izhevsk Technical University and Izhevsk Medical Academy. We are conducting a study which aims to discover the reasons for the poor health and very high risk of dying among working-age men in Izhevsk. We have selected your household because we believe X is/was part of this household. Is this correct?'

If yes: go to point 4

If no: go to point 3

Say: 'Do you know the address of X?'

If yes: go to that address and begin again at point 1

If no: abandon interview and report to office

Say: 'How many people here lived/ have lived with X throughout the last 6 months.'

If nobody: go to point 5

If one person: use this person

If more than one person: instruction to interviewer: complete the table people and select the person highest on the list who answers 'yes'. If nobody answers yes, pick the highest person on the list available

Say: 'Is there anyone living here (control) /who was living with X at the time of death (case) who knows/knew the index well enough to be able to answer questions about his circumstances and behaviour?'

If nobody: go to point 6

If one person: use this person

If more than one person: interviewer: select the best person according to your judgment.

Say: 'Is this because X has recently moved?'

If yes: ask for the new address; go to the new address and then begin again at point 1

If no address is available: abandon interview and report to office

If no: abandon interview and report to office

<b>Relationship to index</b>	<b>Do they live with the index? (Y/N)</b>	<b>Have they had day to day contact<sup>a</sup> with the index? (complete for Y in previous column)</b>
Wife		
Sister 1 (over 18)		
Sister 2 (over 18)		
Sister 3 (over 18)		
Mother		
Brother 1 (over 18)		
Brother 2 (over 18)		
Brother 3 (over 18)		
Father		
Child 1 (over 18)		
Child 2 (over 18)		
Child 3 (over 18)		
Other (over 18)		

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<sup>a</sup> The phrase 'day to day contact' is a colloquial phrase. The phrase does not ask whether the respondent has seen the index every single day over the last 6 months or other period. It is actually a very subjective question intended to determine whether the contact that the index recently had with the index is sufficient for them to report on the index's observable behaviour and characteristics. The translation into Russian should capture this concept.



Figure 1 Flow chart of respondent selection: case proxy

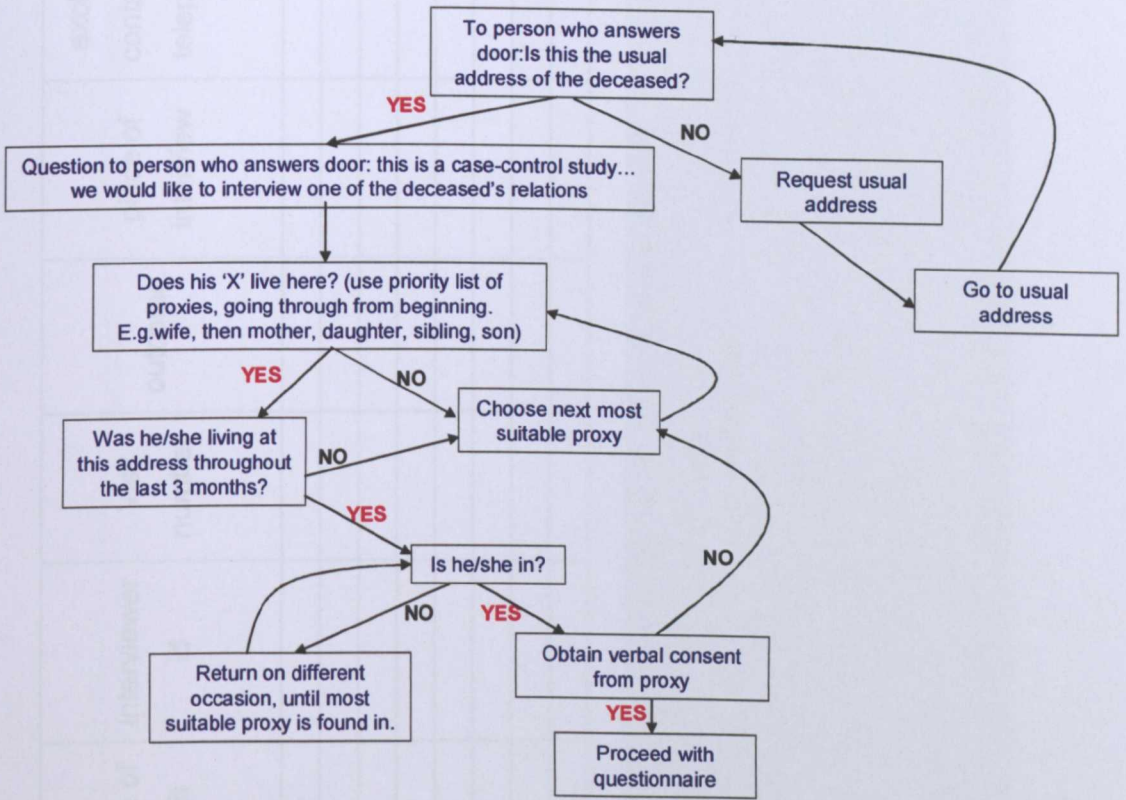


Figure 2 Flow chart of respondent selection: control and control proxy

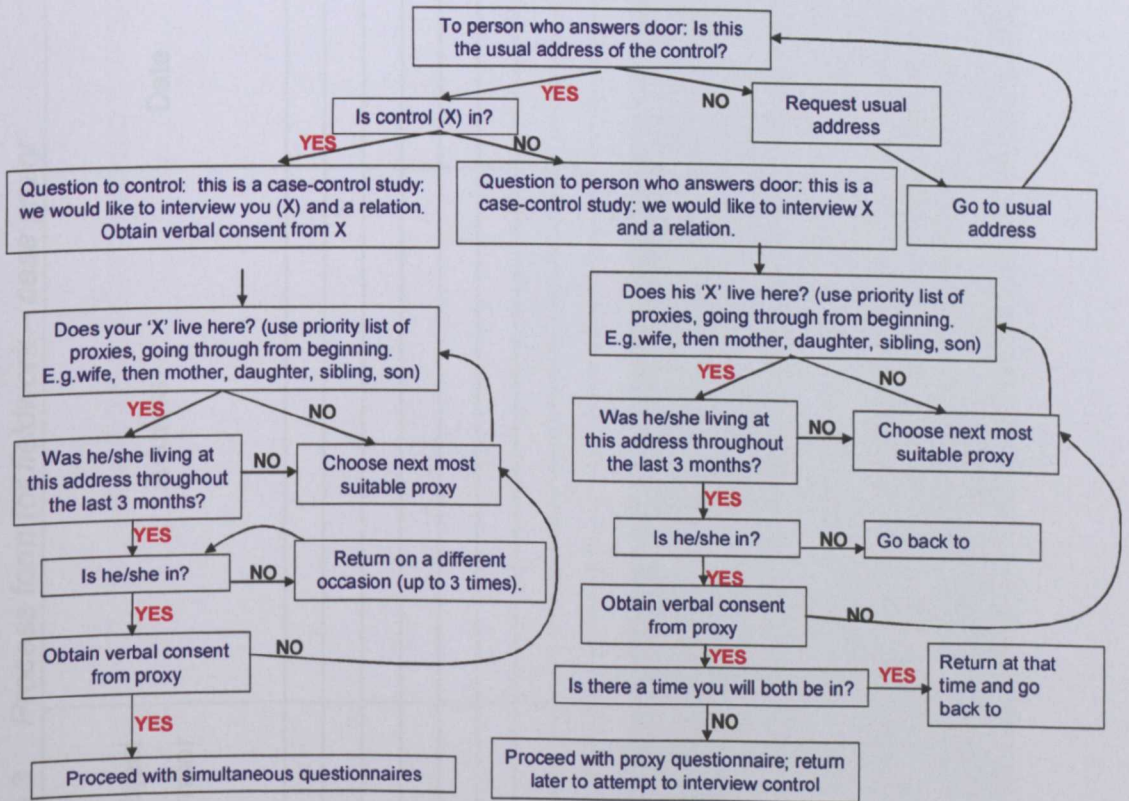


Figure 3 Process form for fieldwork – case proxy

Subject number	Address	Date	Time of visit	Interviewer id	Visit number	outcome	place of interview	exclude/ contact by telephone ?

Code for outcome:	Codes for place of interview
1 - interview of proxy 21 - the proxy has refused 22 - the proxy will be absent for a long period of time 23 - the proxy interview is postponed (work with given subject will be continued) 5 - the case lived alone 7-# - door is closed (indicate visit number) 81 - the address does not exist 82 - the case did not live at the listed address and the true address is unknown 83 - the case did not live at the listed address, and the true address is outside Izhevsk, 84 - the case did not live at the listed address, but the true address is known (in Izhevsk) (work with given subject will be continued) 9 - other	L - home (listed address ) C - home (corrected address) O - other place



Figure 4 Process form for fieldwork – control and control proxy

Subject number	Address	Date	Time of visit	Interviewer id	visit number	outcome	place of interview	exclude/ contact by phone?
<p><b>Code for outcome:</b></p> <ul style="list-style-type: none"> <li>1 - interview of the proxy and the control</li> <li>21 - interview of control only, the proxy has refused</li> <li>22 - interview of control only, the proxy will be absent for a long period of time</li> <li>23 - interview of control only, proxy interview is postponed (work with given subject will be continued)</li> <li>31 - interview of proxy only, the control has refused</li> <li>32 - interview of proxy only, the control will be absent for a long period of time</li> <li>33* - interview of proxy only, control interview is postponed</li> <li>41 - refusal of both</li> <li>42 - both will be absent for a long period of time</li> <li>43 - no interviews obtained for any combination of reasons above, work will continue with given subject (work with given subject will be continued)</li> <li>5 - the control lives alone</li> <li>6 - the control has died</li> <li>7-# - door is closed (indicate visit number)</li> <li>81 - the address does not exist</li> <li>82 - the control does not live at the listed address and the true address is unknown</li> <li>83 - the control does not live at the listed address, and the true address is outside Izhevsk,</li> <li>84 - the control does not live at the listed address, but the true address is known (in Izhevsk) (work with given subject will be continued)</li> <li>9 - other</li> </ul>								
						<p><b>Codes for place of interview</b></p> <ul style="list-style-type: none"> <li>L - home (listed address)</li> <li>C - home (corrected address)</li> <li>O - other place</li> </ul>		

## **1.2 Subject information sheet (case proxy)**

### **Izhevsk family health study**

#### **What is the study about ?**

This study is to discover the reasons for the poor health and very high risk of dying among working-age men in Urdmurtia. This is being done by interviewing family and friends of men aged between 25 and 54 years in Izhevsk to find out more about their family and social situation. By comparing the circumstances of men who have died with the circumstances of those who have survived we will be able to find factors that may cause these premature deaths and so help prevent such tragedies in the future.

#### **What are you being asked to do ?**

We would like to interview you to help us find out more about the factors that cause these premature deaths in Urdmurtia. In the interview you will be asked some questions about your own life and habits and questions about the life and habits of a male member of your household. The interview will take approximately one hour.

#### **Why should you take part ?**

Doctors and scientists are still unclear about why men in Urdmurt, and Russia as a whole, have such poor health. This study is important because it will help provide essential information to citizens and the government about steps that can be taken to improve health and reduce mortality. Your decision to take part should be entirely voluntary. If you do not wish to take part this will not affect your access to or standard of medical care in any way.

#### **What information will be collected ?**

The interviewer will ask you questions about you and the life and habits of the male members of your family and close friends. The questions we will ask about you will include your age and relationship to the other family members (that is are you wife, mother, son, daughter etc. or friend). Questions will also be asked about men in your family including their age, physical health, use of health services, education and employment history, quality of family and social relationships, physical exercise, alcohol drinking and smoking habits.

#### **Will this information be kept confidential ?**

The information collected in the study will be used only for the purposes of scientific analysis. It will be kept secure by researchers at the Izhevsk Medical Academy. No information that will enable you or your family members or friends to be identified will be given to any agencies, government departments or individuals. Scientific analyses will be based on anonymous data only. Names and addresses will be removed from the data before analysing them.

#### **Who is doing the study ?**

The study is being undertaken by the Izhevsk Medical Academy and the Technical University of Izhevsk in collaboration with researchers from the United Kingdom and Germany. The study has the full support of the government of the Udmurt Republic and the local administration of the city of Izhevsk.

#### **Further information**

If you would like to find out more about this study please ring XXXXXX on Tel : XXXXXXXX.

## **Appendix 2**

### **Description of questionnaire survey fieldwork procedures (April 2004)**

by Lyudmilla Saburova

## **Summary**

### **1. Work with lists of subjects**

Preparation of fieldwork (checking of addresses, locating addresses on the map, deletion of non-existent addresses, distribution of addresses to interviewers).  
Monitoring of fieldwork (marking process indicators on lists, checking that lists correspond with the navigation sheet data and interview database).

### **2. Preparation of interviewers (selection, training)**

### **3. Instructions for interviewers**

### **4. Management of interviewers**

This consists of two control processes – control of conduct of the interview, and control of interview completion.

Conducting of interview control - phone questioning, repeat visits

Interview completion control – before entry and after checking of logical mistakes.

### **5. Fieldwork management**

Distribution of addresses, questionnaires, accompanying documents (information sheet, navigation sheet, proxy-selection protocol), respondent fee. Receipt of completed questionnaires and accompanying documents (proxy-selection protocol, navigation sheet). Changing selection (replacement of the addresses that were not found, the addresses where the interviews were not carried out).

Preparation of questionnaires for data entry.

### **6. Reporting of fieldwork.**

## THE DESCRIPTION OF THE PROCEDURES

1. **Work with lists of cases and controls ( described in EA instruction).**

2. **Preparation of interviewers**

### 2.1 *Selection criteria*

age between 30-55; at least 1 year's work experience as an interviewer; reference from previous employer.

### 2.2 *Training*

#### *Necessary information*

- knowledge of objectives and the main tasks of research,
- knowledge of main terminology (case, control, proxy, main group, control group),
- knowledge of techniques and the main procedures of fieldwork,
- knowledge of respondents' rights, ethic standards,
- knowledge of safety measures

#### *Necessary skills*

- contacting potential respondent and members of his family,
- selection of suitable respondent,
- correct completion of the questionnaire and accompanying documents.

#### *Training techniques*

During the preliminary talk interviewers are informed of objectives, tasks, research structure and general information on techniques.

Two methods of training are employed

Training in how to contact a respondent and selection of a suitable respondent – they think through the variety of possible respondent reactions to interviewer 's visit. They learn specific skills to help elicit respondent's agreement; to react to individual peculiarities of the respondent's character (fear of opening the door, anger, doubts, lack of time). Training is carried out by a manager or a supervisor.

Questionnaire completion training comprises a practice interview with a pretend respondent. Interviewers develop skills of good navigation through the questionnaire (correct use of skips, answering all appropriate questions), questions and question response reading (where necessary). Special attention is paid to training interviewer not to give his own interpretation to questions, not to comment on answer categories, and not to change respondents' words in open responses. Interviewers interview each other, a supervisor or a manager in role plays.

### **3. Interviewers instructions**

#### **3.1 Selection of respondents**

In contrast to many other surveys, for this research particular men are chosen as subjects, and cannot be replaced by other men that fulfill similar conditions: i.e. the interviewers are provided with the address, first name, last name, patronymic name and personal identification number of a subject.

If the subject didn't or doesn't live at that address, it is necessary to find out the correct address. If the correct address cannot be identified, this subject is excluded from the survey. If a case or control lived or lives alone, the interview is not carried out. If a subject did not have or does not have his own family, but lived or lives with another family (tenants, neighbours in a dormitory or communal apartment), it is necessary to find out whether the man communicated or communicates with them, whether they know the man, and whether they know about the details of his life during the past year. If they do not fulfill these criteria, the interview should not be carried out. If they do, then the interview may be done.

If the subject is a case (dead), then we interview someone close to that subject, a proxy. If the subject is a control (alive), we interview a proxy and the man themselves, and these two interviews should be done simultaneously. It is necessary to select a proxy that is knowledgeable on the details of the subject's life during the past year. To select the best possible proxy, the interviewers should follow the proxy selection protocol, where everything is described step by step. The proxy selection protocol is distributed to interviewers with other subject details, and is returned, completed, with the questionnaire to the fieldwork manager.

#### **3.2 Interview sequence**

##### ***Preliminary contact with respondent***

Preliminary contact addresses the following issues:

- making contact in person (interviewer) and an opportunity to explain the purpose of the visit
- verification of address and personal identification of case/control
- selection of proxy
- provision of necessary information about the research: its objectives, tasks, anonymity guarantee, type of questions to be asked. The interviewer reads the information sheet to the respondent, or the respondent reads it themselves, as they wish. The information sheet is left with the family, except if the respondent objects to this. The interviewer points out the phone number in the information sheet which the respondents may call if they require any additional project information.
- opportunity to motivate the respondent to participate. The interviewer should emphasise that hundreds of families in Izhevsk have already taken part in the project, and the results of the research will inform important policy decision-making on family health problems, and that information received from every



family is very important for the project. If it is evident that the family income level is low, the interviewer can offer a financial incentive for participation.

- obtain agreement of respondent to participate. After the respondent has received all information on the research, the interviewer should ask him/her once again whether he agrees to participate. If yes, the interviewer marks this agreement on the questionnaire title page.

#### *Interview location*

The interview should be carried out wherever it is convenient for the respondent (at home, at the workplace, in a public place), provided the necessary confidentiality is observed. If possible, the location should also be convenient to the interviewer. It is important that no other people are present during the interview (other family members, neighbors, colleagues). If the control is being interviewed, the control proxy must not be in the same room and vice versa. The interviewer should ask the respondent to find a place where they can be alone. It is important to conform that members of the respondent's family cannot hear his/her answers, including when the interview is carried out in a separate room. The interviewer should record all circumstances affecting the privacy of the interview in the last section of the questionnaire.

#### *Timing of the interview*

The interview may be carried out at any time convenient to the respondent. It is important that the timing of the interview corresponds to general ethical standards: i.e. interviews should not take place earlier than 10 a.m. or later than 9 p.m., except for repeated visits when the time is arranged beforehand. The duration of the interview is 25 to 40 minutes. The interviewer should not take large breaks during the interview (breaks that are more than 30 minutes). Additionally, the interviewer should not leave the interview location before the interview is over. The interviewer must mention all breaks, their causes and duration in the last section of the questionnaire.

#### *The interview process*

Two respondents in the control's family should be interviewed. Only if it is impossible to interview both the control and a proxy, should only one of them be interviewed. The following situations may arise that result in only one interview being conducted:

- one of them is absent or will be absent for a long time,
- one of them refuses to participate in the project,
- the interviewing of one of them is impossible due to other reasons (physical disability, mental disease).

NB – it is necessary to determine whether all the members of the control's family were identified through the selection protocol and there is no one available to be interviewed.

If the control strongly objects to the interview of a proxy, then the proxy should not be interviewed. When both a control and control proxy are interviewed, it is necessary that they are interviewed simultaneously (when there are two interviewers)

or one straight after the other without any breaks (when there is only one interviewer). If this is impossible, then the interviewer must interview the control proxy first, followed by the control. Only in the specific situation that a control refuses to be interviewed at the appointed time, or is going somewhere in the immediate near future, can the control be interviewed before his proxy.

#### *At the end of the interview*

After the completion of the interview it is necessary to thank the respondent and offer him a predetermined financial reward. The interviewer should mention the possibility of a repeated visit or a phone call in case additional clarifications to the interview are found to be necessary. If the respondent agrees, the interviewer should mark this on the interview, and should take a contact phone number (home or work). After the interviewer has left the room where the interview took place, she/he must complete the navigation sheet.

### **3.3 Completion of the navigation sheet**

The navigation sheet should be completed after each visit, irrespective of the outcome. The following data should be entered on the navigation sheet:

- Subject identification number
- Interviewer number
- Address
- Date and time of the visit
- Visit number (to family, not address)
- Visit outcome, according to code system
- Where the result of the interview was successful: the place of the interview and, if possible, a contact number of the respondent
- Where the result of the interview was not successful: indication that this subject is excluded, once it is evident that there is no further point in continuing to attempt to include him

The navigation sheet is returned to the fieldwork manager along with all other documents. The interviewer should include all comments and remarks that arise during the interview process on the navigation sheet. If the interviewer finds it difficult to select one code, they should write longhand the outcome of the interview.

### **3.4 Completion of the questionnaire**

The questioning is carried out in the form of an interview. The interviewer reads each question out as it is written in the questionnaire, except where it is marked that they should answer the question themselves (question about sex of the person). The interviewer is required to read out all answers, except those which the respondent easily answers without need of assistance (nationality, birthplace) and “yes/no” questions.

Options encoded “98” and “99” are not read to the respondents. If the respondent finds it difficult to answer or does not want to answer the question, the corresponding option is selected by the interviewer. Questions presented as tables in the

questionnaire are read out and completed line by line. These questions investigate life events of the subject and his pattern of alcohol consumption. The section on the socioeconomic situation of the family contains two questions that require presentation of cards to the respondent which list possible answer options, to assist the respondent in selecting all that apply (these are multiple choice questions). If the respondent is unable to read the card themselves, the interviewer should read it out, repeating each option several times.

Open questions should be accurately completed by the interviewer, according to the respondent's response. These should be legible and avoid abbreviations (except those that are commonly used).

Instructions on which sentences should be read out, and which are only for the interviewer, are on the second page of the questionnaire. On the same page all instructions on how to complete the questionnaire are also found. Transition phrases, indicated by the use of a different font defined at the beginning of the interview must be read out by the interviewer. Additionally, it is very important to pay attention to the instructions given with every question which indicate how many options should be selected (one or multiple). Every interviewer must follow all the transitions in the questionnaire for the interview to be correctly completed, and to avoid loss of important information. Failure to do this will be regarded as failure in the completion of the questionnaire.

During the interview, the following are not allowed:

- any attempts to help to the respondent, delivery of the question in interviewer's own formulation or any prompting
- interviewer's own interpretation of respondent's answers when they do not correspond to the provided options. If the respondent gives a response which the interviewer finds it difficult to identify with the provided options (in the questions about official status or diseases), the answer of the respondent should be written alongside the option "other" as it was said by the respondent.
- omission of any questions if the interviewer thinks they can predict the answer. E.g. the interviewer must not select "pension" in the question about source of income without the respondent saying this, even if the respondent has already mentioned that he is retired at the moment
- giving the questionnaire to the respondent to complete themselves

If any problems occur during the interview, the interviewer should contact their manager or the supervisor, or note down all the information given by the respondent and query how to deal with it afterward the interview.

The questionnaire is completed using a blue biro. Any corrections that arise during the interview are made by the interviewer himself, using the same biro. Use of correctors (e.g.. tip-ex) is not allowed.

#### **4. Control of interviewers' work**

There are 4 levels of quality-control:

#### **4.1 Visual**

The following is checked:

- all documentation (questionnaire, proxy-selection protocol, navigation sheet)
- compliance with all rules relating to navigation sheet and proxy-selection protocol
- completion of the questionnaire. The questionnaire is accepted only if all necessary questions are answered, including open questions.

Visual control is carried out by the fieldwork manager

#### **4.2 Logical control following first data entry**

This second stage of checking takes place if logical errors are identified (transitions were not made or were made incorrectly, contradictions in answers, etc.). Logical control is carried out by the data entry manager and fieldwork manager. Together with the interviewer, they also carry out full contents analysis of questionnaires.

#### **4.3 Authenticity of received data.**

10% of the selected questionnaires are checked by the partial repeat questioning. Questioning is carried out by phone, or in person if there is no phone on the home of the respondent. The following issues are addressed:

- confirmation that the interview took place
- date of the interview
- the technique: interview or questioning
- duration of the interview
- use of the cards and their number
- respondent payment
- respondent's impressions of the interview and interviewer

Additionally, the answers to 2 or 3 questions are also checked. These are usually questions investigating objective characteristics of the respondent/subject - about education, birth place, place of work, alcohol consumption, visits to clinic.

Addresses used for such checking are selected by the fieldwork manager. Repeat interviews are done by experienced interviewers, provided they do not know the name of the interviewer being checked. Some interviewers are recruited from employees who are not participating in the project.

#### **4.4 Additional checking**

There are two additional methods of control. Firstly, all questionnaires are checked by comparison of respondents' dates of birth as recorded in the lists of cases and controls, with the dates of birth recorded in the questionnaire. If any discrepancy is found, a repeat interview is necessary. Additionally, a repeat interview is necessary if the supervisors have any doubts in the authenticity of data recorded for some individual or groups of questions. Additional checking is made by the fieldwork supervisor.

If any mistakes or falsification are identified to be due to failure by any interviewer to comply with guidelines for interview procedures, all questionnaires conducted by this interviewer are retrospectively checked. Wrong questionnaires are removed from the database, and the interview is repeated if possible.

## **Appendix 3**

### **Final English version of the case proxy questionnaire**

**Izhevsk Family Study**  
**Case proxy questionnaire**  
**Cover Sheet: to be completed by the interviewer**

Subject number

--	--	--	--	--	--

Date of interview

DD 

--	--

 MM 

--	--

 YYYY 

--	--	--	--

Interviewer first name

.....

Interviewer last name

.....

Interviewer code

--	--	--	--

Time started

--	--

 : 

--	--

Time ended

--	--

 : 

--	--

**Having read the information sheet, are you willing to be interviewed and for the information collected to be used for the purposes of this scientific study?**

Has respondent read the study information sheets?

Yes 

--

Has respondent given verbal consent?

Yes 

--

For office use only:

**Instructions to interviewer:**

All questions, unless explicitly stated otherwise, relate to circumstances or events up until the time of death of the deceased, and **NOT** later.

Some questions ask about the behaviour of *the deceased* during the year before death (G11, some questions in section L). For these questions, please disregard any changes in behaviour that occurred in the last few months before death due to ill health.

How to fill in this questionnaire:

- where there are numbers, circle one or more as indicated for each specific question
- where there are lines, fill in with text
- where there are small boxes, fill in with figures and leading zeros if

0	1	0
---	---	---

necessary. E.g. 'ten' would be:

Whenever you come across '*the deceased*' please replace it with 'your husband' or 'your son' or whatever else is most appropriate.

Different fonts will be used to help you distinguish between different types of phrases:

**Questions, to be read out to the respondent, will be written like this.**

**Instructions, to be read out to the respondent, will be written like this.**

*Instructions for you, the interviewer, will be written like this. These should not be read out*



**Questionnaire: case proxy**

**A1. Interviewer! Please note the sex of the respondent:**

- 1 male
- 2 female

**I would like to begin by asking you some questions about yourself**

**A2. How old are you?**

years

- 97 difficult to answer
- 98 refuse to answer

**A3. What is your date of birth?**

DD  MM  YYYY

- 97 difficult to answer
- 98 refuse to answer

**A4. What is your nationality?**

*Please circle the single most appropriate answer.*

- 1 Russian
- 2 Urdmurt
- 3 Tatar
- 4 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**A5. Please could you tell me the region in which you were born?**

*Please circle the single most appropriate answer.*

- 1 Izhevsk ⇒ go to A7
- 2 Other part of Udmurtia
- 3 A different oblast of Russia
- 4 A part of the former Soviet Union outside Russia
- 5 Outside the former Soviet Union
- 97 difficult to answer
- 98 refuse to answer

**A6. Was the place you were born in an urban or a rural area?**

*Please circle the single most appropriate answer.*

- 1 urban
- 2 rural
- 97 difficult to answer
- 98 refuse to answer

**A7. Could you tell me how long you have continuously lived in Izhevsk?**

*Please circle the single most appropriate answer.*

- 1 less than 6 months
- 2 6 months - 1 year
- 3 more than 1 year but less than 5 years
- 4 more than 5 years but less than 10 years
- 5 over 10 years but not my whole life
- 6 since birth (excluding army and temporary periods away of up to 5 years)
- 97 difficult to answer
- 98 refuse to answer

**A8. What is your current marital status? Are you:**

*Please circle the single most appropriate answer.*

- 1 Living together with a spouse in a registered marriage
- 2 Living together with a spouse but not in a registered marriage
- 3 Divorced or separated
- 4 Widowed
- 5 Never married
- 97 difficult to answer
- 98 refuse to answer

**I would now like to ask about your education and occupation**

**A9. What is your level of education?**

*Please circle the single most appropriate answer.*

- 1 incomplete secondary
- 2 complete secondary
- 3 professional school
- 4 specialised secondary
- 5 incomplete higher
- 6 higher
- 97 difficult to answer
- 98 refuse to answer

**A10. Are you currently in regular paid employment?**

*Please circle the single most appropriate answer.*

- 1 yes ⇒go to A14
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**A11. Are you...**

*Please circle all answers which apply*

- 1 in irregular paid work
- 2 unemployed, seeking work
- 3 student
- 4 retired, except for retirement due to invalidity ⇒go to A13
- 5 retired due to invalidity ⇒go to A13
- 6 unemployed, not seeking work
- 7 housewife
- 8 on maternity leave
- 9 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**A12. What was the main reason for ceasing regular paid employment?**

*Please circle the single most appropriate answer.*

- 1 could not find a job after finishing education
- 2 was made redundant
- 3 a temporary job ended
- 4 was fired
- 5 gave up voluntarily due to unsatisfactory work salary/work conditions
- 6 gave up work because of ill health
- 7 on maternity leave
- 8 gave up my job for other reasons (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**A13. How long ago did you cease regular paid employment?**

*Please circle the single most appropriate answer.*

- 1 have never been in regular paid employment ⇒go to A18
- 2 within the past week
- 3 more than 1 week but less than 1 month ago
- 4 more than 1 month but less than 6 months ago
- 5 more than 6 months but less than 1 year ago
- 6 over 1 year ago )
- 97 difficult to answer )⇒go to A18
- 98 refuse to answer )

I would now like to ask you some questions about your main occupation over the past year

**A14. What was your main occupation during the past year?**

*Please answer in your own words.*

1

.....
.....
.....
.....
.....

- 97 difficult to answer
- 98 refuse to answer

**A15. What has been your main occupational status during the past year?**

*Please circle the single most appropriate answer.*

- 1 Senior official or office top manager
- 2 Manager of department or branch office
- 3 Production and operation department manager
- 4 Physical and engineering science associate professional
- 5 Life science and health associate professional
- 6 Office clerk without higher education
- 7 Skilled worker
- 8 Unskilled worker
- 9 Entrepreneur
- 10 Other
- 97 difficult to answer
- 98 refuse to answer

*Interviewer! If there are any discrepancies between the respondent's occupational status and education, select the response for A15 according to occupational status. For example, a nurse with higher education is marked as 'office clerk without higher education', point '6, and a primary school teacher with secondary special education is marked as 'life science and health associate professional', point '5', etc. '*

**A16. What type of firm or organisation have you mainly worked for during the past year?**

*Please circle the single most appropriate answer.*

- 1 State/local enterprise/authority
- 2 Cooperative/employee owned firm
- 3 A private company
- 4 Joint state and private ownership
- 5 Other (specify) .....

- 97 difficult to answer
- 98 refuse to answer

**A17. In what branch of industry have you mainly worked during the past year?**

*Please circle the single most appropriate answer.*

- 1 civil service
- 2 education, culture and media
- 3 banks or other financial institutions
- 4 healthcare or social services
- 5 service industry
- 6 agriculture
- 7 industry, construction
- 8 transport, communications
- 9 military/police
- 10 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**A18. Do you have any sources of income (if you are in regular paid employment, exclude earnings from your main workplace)?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to A20.
- 98 refuse to answer )

**A19. What are these sources of extra income?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 Pension (any kind)
- 2 Occasional/irregular work
- 3 Social benefits (any kind)
- 4 Private enterprise
- 5 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**A20. If you are registered disabled, how long ago were you registered?**

*Please circle the single most appropriate answer.*

- 1 not applicable
- 2 within the last 6 months
- 3 6 months - 1 year ago
- 4 2 - 5 years ago
- 5 6-10 years ago
- 6 over 10 years ago but not your whole life
- 7 had/have always been registered disabled
- 97 difficult to answer
- 98 refuse to answer

I would like to ask you your views about the area you live in:

**B1. What is your view of the general state of this neighbourhood as a place to live?**

*Please circle the single most appropriate answer.*

- 1 very good
- 2 good
- 3 fair
- 4 poor
- 5 very poor
- 97 difficult to answer
- 98 refuse to answer

**B2. Please select the phrase from the following five choices that best describes the people in your neighbourhood.**

*Please circle the single most appropriate answer.*

- 1 Everyone is friendly towards each other
- 2 Most of them are friendly towards each other
- 3 Some of them are friendly towards each other
- 4 A few of them are friendly towards each other
- 5 No one is friendly towards each other
- 97 difficult to answer
- 98 refuse to answer

**B3. With regard to level of crime, how do you see this neighbourhood?**

*Please circle the single most appropriate answer.*

- 1 there is a high level of crime
- 2 there is a moderate level of crime
- 3 there is a low level of crime
- 97 difficult to answer
- 98 refuse to answer

Now a few questions about whether you or any other member of your household have been a victim of crime

**B4. Please indicate which, if any, of the following crimes have affected this residence or things belonging to members of the household during the past year**

*Multiple responses are permitted. Please circle all that apply.*

- 1 a car or other vehicle was stolen
- 2 something was stolen out of a car
- 3 a vehicle was damaged or destroyed by vandals or people out to steal
- 4 someone got into this residence without permission and stole something
- 5 someone got into this residence without permission and caused damage
- 6 someone attempted to get into this residence without permission
- 7 something was stolen from outside the residence (from garage, dacha, etc)
- 8 deliberate damage was done to this residence or anything outside it that belonged to someone in this household
- 9 other (specify) .....
- 10 none of the above
- 97 difficult to answer
- 98 refuse to answer

**B5. I now want to ask you which, if any, of the following crimes were committed against you personally during the past year**

*Multiple responses are permitted. Please circle all that apply.*

- 1 something you were carrying was stolen out of his hands or from his pockets, bag or case
- 2 something was stolen from a cloakroom, office or car or anywhere else you left it
- 3 something of yours was deliberately damaged or tampered with
- 4 someone physically assaulted you
- 5 someone threatened to physically assault you
- 6 you were sexually interfered with, assaulted or attacked by someone you knew or a stranger
- 7 Other (specify) .....
- 8 none of the above
- 97 difficult to answer
- 98 refuse to answer

**B6. I now want to ask you which, if any, of the following crimes were committed against *the deceased* during the year before death**

*Multiple responses are permitted. Please circle all that apply.*

- 1 something he was carrying was stolen out of his hands or from his pockets, bag or case
- 2 something was stolen from a cloakroom, office or car or anywhere else he left it
- 3 something of his was deliberately damaged or tampered with
- 4 someone physically assaulted him
- 5 someone threatened to physically assault him
- 6 he was sexually interfered with, assaulted or attacked by someone he knew or a stranger
- 7 Other (specify) .....
- 8 none of the above
- 97 difficult to answer
- 98 refuse to answer

**B7. I now want to ask you which, if any, of the following crimes were committed against any other member of this household during the past year**

*Multiple responses are permitted. Please circle all that apply.*

- 1 something they were carrying was stolen out of his hands or from his pockets, bag or case
- 2 something was stolen from a cloakroom, office or car or anywhere else they left it
- 3 something of theirs was deliberately damaged or tampered with
- 4 someone physically assaulted them
- 5 someone threatened to physically assault them
- 6 they were sexually interfered with, assaulted or attacked by someone they knew or a stranger
- 7 other (specify) .....
- 8 none of the above
- 9 not applicable
- 97 difficult to answer
- 98 refuse to answer



I would now like to ask you some additional questions about the people who live in the deceased's household:

**C1 How many people currently live in his household?**

people

97 difficult to answer

98 refuse to answer

**C2 How many people, including *the deceased*, lived in his household at the time of the death?**

people

97 difficult to answer

98 refuse to answer

**C3 Have any new people moved in or out of his household since *the deceased* died?**

*Please circle the single most appropriate answer.*

1 yes

2 no

97 difficult to answer

98 refuse to answer

C4 I am now going to ask you some questions about the structure of the deceased's household at the time of his death.

*Interviewer! This table excludes the respondent and the deceased  
Interviewer! Where options are given, please circle the appropriate response*

First name	Relation-ship to deceased	Sex	Age (yrs)	education	Contributed to household income?
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>
.....	<input type="text"/>	M F	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Relationship codes:**

- 1 spouse or partner
- 2 parent
- 3 brother
- 4 sister
- 5 daughter
- 6 daughter in law
- 7 son
- 8 son in law
- 9 grandchild
- 10 other relatives
- 11 unrelated lodger/friend
- 97 difficult to answer
- 98 refuse to answer

**Education codes:**

- 1 incomplete secondary
- 2 complete secondary
- 3 professional school
- 4 specialised secondary
- 5 incomplete higher
- 6 higher
- 9 not applicable
- 97 difficult to answer
- 98 refuse to answer

**Contribution to income**

**codes:**

- 1 Yes
- 2 No

**I would now like to ask you some questions about the home of the deceased at the time of his death**

**C5. What type of dwelling is it?**

*Please circle the single most appropriate answer.*

- 1 hostel
- 2 shared/communal flat
- 3 flat, sole use
- 4 part of shared house
- 5 house, sole use
- 6 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**C6 What type of building is it?**

*Please circle the single most appropriate answer.*

- 1 wooden house
- 2 brick house
- 3 house built from concrete blocks
- 4 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**C7. Who owned this dwelling at the time of his death?**

*Please circle the single most appropriate answer.*

- 1 a member or members of the household / flat privatized
- 2 the state or municipality / flat unprivatized
- 3 someone who does not live in the house (specify) .....
- 4 other (specify) ..... ) ⇒ go to C9
- 97 difficult to answer )
- 98 refuse to answer )

**C8. How did a member or members of his household come to own the dwelling?**

*Please circle the single most appropriate answer.*

- 1 built it entirely or partially themselves
- 2 purchased it
- 3 obtained it through privatisation free of charge
- 4 inherited it or obtained it as a gift
- 5 exchanged it with a different household without adding money
- 6 exchanged it with a different household and added some of own money
- 7 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**C9. How many rooms, excluding kitchen and bathroom, are there in the dwelling in total?**

rooms

97 difficult to answer

98 refuse to answer

**C10. How many rooms are used for sleeping in the dwelling. Please include rooms that also have other functions.**

rooms

97 difficult to answer

98 refuse to answer

**C11. How many utility rooms are there in the dwelling in total. By utility rooms, I mean kitchen, bathroom, toilet, storage room, entrance hall, converted balcony**

rooms

97 difficult to answer

98 refuse to answer

**C12. Which of the following amenities did his household have access to at the time of his death?**

*Multiple responses are permitted. Please circle all that apply.*

1 toilet, connected to sewerage system with running water

2 hot water supplied

3 cold water supplied

4 central heating

5 gas or electric oven

6 telephone

7 electricity

97 difficult to answer

98 refuse to answer

The following questions relate to the economic situation of his household at the time of death of the deceased

**C13. Which of the following properties did his household entirely or partly use or own in addition to this home?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 summer dacha or garden house
- 2 all-season dacha or countryside house
- 3 another house in city
- 4 another flat or room in city
- 5 workshop or place for personal enterprise
- 6 shop or kiosk for street trade
- 7 Other (specify) .....
- 8 none
- 97 difficult to answer
- 98 refuse to answer

**C14. Which of the following things did his household own?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 a car
- 2 a motorcycle
- 3 livestock
- 5 modern television
- 6 video
- 7 videocamera
- 8 computer
- 9 automatic washing machine
- 10 microwave
- 11 telephone
- 12 hifi
- 13 fridge
- 14 none of the above
- 97 difficult to answer
- 98 refuse to answer

**C15. On what kind of income did his household rely during the year before the death of the deceased?**

*Interviewer! Show the respondent card No. C15*

*Multiple responses are permitted. Please circle all that apply.*

- 1 regular salaries
- 2 occasional salaries
- 3 income/revenue from business or individual labour
- 4 income/revenue from agriculture
- 5 income from bank interest or dividends
- 6 age pensions
- 7 invalidity pensions
- 8 welfare: social benefits (including social privileges)
- 9 welfare: child benefit
- 10 scholarships
- 11 help of relatives
- 12 other
- 13 none
- 97 difficult to answer
- 98 refuse to answer

**C16. Did *the deceased* contribute to the household income in the few months before his death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**C17. What proportion of the household's monthly income was normally spent on food in the year before the death of *the deceased*?**

*Please circle the single most appropriate answer.*

- 1 less than half of the household's income
- 2 about half of the household's income
- 3 more than half of the household's income
- 97 difficult to answer
- 98 refuse to answer

**C18. Which of the phrases below best describes this household's financial situation during the year before the death?**

*Interviewer! Show the respondent card No. C18*

*Please circle the single most appropriate answer.*

- 1 We were sometimes unable to purchase basic necessities (food, communal services, essential clothing or inexpensive medicine)
- 2 We were able to purchase basic necessities, but not expensive goods for long-term use
- 3 long-term use
- 4 We were occasionally able to purchase expensive goods for long-term use
- 5 We were able to purchase expensive goods for long-term use, but not things like houses, flats or expensive cars
- 97 We were able to purchase expensive goods for long-term use such as houses, flats or expensive cars
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you a few questions about *the deceased's* parents.

*Interviewer! Do not ask D1-D3 if you already know that the mother is alive, but complete D1:*

**D1. Was the mother of *the deceased* alive when he died?**

*Please circle the single most appropriate answer.*

- 1    yes    ⇒**go to D4.**
- 2    no
- 97   difficult to answer   ⇒**go to D4.**
- 98   refuse to answer    ⇒**go to D4.**

**D2. When did his mother die?**

*Please circle the single most appropriate answer.*

- 1    within the last year
- 2    1 - 5 years ago
- 3    6 - 10 years ago
- 4    more than 10 years ago
- 97   difficult to answer
- 98   refuse to answer

**D3. How old was his mother when she died?**

years

- 97   difficult to answer
- 98   refuse to answer



*Interviewer! Do not ask the D4-D6 if you already know that the father is alive, but complete D4:*

**D4. Was the father of the deceased alive when he died?**

*Please circle the single most appropriate answer.*

- 1    yes    ⇒go to E1
- 2    no
- 97   difficult to answer    ⇒go to E1
- 98   refuse to answer    ⇒go to E1

**D5. When did his father die?**

*Please circle the single most appropriate answer.*

- 1    within the last year
- 2    1 - 5 years ago
- 3    6 - 10 years ago
- 4    more than 10 years ago
- 97   difficult to answer
- 98   refuse to answer

**D6. How old was his father when he died?**

years

- 97   difficult to answer
- 98   refuse to answer

I would now like to ask you a series of questions about the personal details of *the deceased* and your relationship with him:

**E1. What was your relationship to the deceased?**

*Please circle the single most appropriate answer.*

- 1 wife/girlfriend/partner
- 2 parent
- 3 brother
- 4 sister
- 5 daughter
- 6 daughter in law
- 7 son
- 8 son in law
- 9 grandchild
- 10 other close relative
- 11 unrelated lodger/friend
- 12 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**E2. For how long had you been continuously living with *the deceased* at the time of his death?**

*Please circle the single most appropriate answer.*

- 1 less than 6 months
- 2 6 months – 12 months
- 3 more than 1 year but less than 5 years
- 4 more than 5 years but less than 10 years
- 5 over 10 years
- 97 difficult to answer
- 98 refuse to answer

**E3. For how many years had you known *the deceased* before his death?**

*Please circle the single most appropriate answer.*

- 1 less than 6 months
- 2 6 months – 12 months
- 3 more than 1 year but less than 5 years
- 4 more than 5 years but less than 10 years
- 5 over 10 years
- 97 difficult to answer
- 98 refuse to answer

**E4. How good was your knowledge of *the deceased's* life during the last year of his life?**

*Please circle the single most appropriate answer.*

- 1 extremely good
- 2 very good
- 3 fairly good
- 4 not very good
- 5 very poor
- 97 difficult to answer
- 98 refuse to answer

**E5. How often did you usually see *the deceased* during the last year before his death?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 once a week
- 4 several times a month
- 5 once a month
- 6 less than once a month
- 97 difficult to answer
- 98 refuse to answer

**E6. At which times of day did you typically see *the deceased* during the working week (Monday - Friday)?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 first thing in the morning
- 2 during the day
- 3 during the evening
- 4 late at night
- 5 no typical time
- 97 difficult to answer
- 98 refuse to answer

**E7. At which times of day did you typically see *the deceased* during the weekend (Saturday, Sunday)?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 first thing in the morning
- 2 during the day
- 3 during the evening
- 4 late at night
- 5 no typical time
- 97 difficult to answer
- 98 refuse to answer

**E8. When did you last see *the deceased* before he died?**

*Please circle the single most appropriate answer.*

- 1 on the day of his death
- 2 on the day before his death
- 3 2-7 days before his death
- 4 more than 1 week but less than 1 month before his death
- 5 more than 1 month but less than 6 months before his death
- 6 over 6 months before his death
- 97 difficult to answer
- 98 refuse to answer

**E9. How old was *the deceased* when they died?**

years

- 97 difficult to answer
- 98 refuse to answer

**E10. What was the date of birth of *the deceased*?**

DD  MM  YYYY

- 97 difficult to answer
- 98 refuse to answer

**E11. What was the nationality of *the deceased*?**

*Please circle the single most appropriate answer.*

- 1 Russian
- 2 Urdmurt
- 3 Tatar
- 4 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**E12. Please could you tell me the region in which he was born?**

*Please circle the single most appropriate answer.*

- 1 Izhevsk ⇒go to E14
- 2 other part of Udmurtia
- 3 a different oblast of Russia
- 4 a part of the former Soviet Union outside Russia
- 5 outside the former Soviet Union
- 97 difficult to answer ⇒go to E14
- 98 refuse to answer ⇒go to E14

**E13. Was the place he was born in an urban or a rural area?**

*Please circle the single most appropriate answer.*

- 1 urban
- 2 rural
- 97 difficult to answer
- 98 refuse to answer

**E14. How long had *the deceased* continuously lived in Izhevsk?**

*Please circle the single most appropriate answer.*

- 1 less than 6 months
- 2 6 months - 1 year
- 3 more than 1 year but less than 5 years
- 4 more than 5 years but less than 10 years
- 5 over 10 years but not his whole life
- 6 since birth (excluding army and temporary periods away of up to 5 years)
- 97 difficult to answer
- 98 refuse to answer

**E15. What was the marital status of *the deceased* at the time of death?  
Was he:**

*Please circle the single most appropriate answer.*

- 1 Living together with a spouse in a registered marriage
- 2 Living together with a spouse but not in a registered marriage
- 3 Divorced or separated
- 4 Widower
- 5 Never married
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you about the education and occupation of the deceased:

**F1 What was the deceased's level of education?**

*Please circle the single most appropriate answer.*

- 1 incomplete secondary
- 2 complete secondary
- 3 professional school
- 4 specialised secondary
- 5 incomplete higher
- 6 higher
- 97 difficult to answer
- 98 refuse to answer

**F2. If the deceased had any professional qualifications, please specify what they are.**

*Please answer in your own words.*

1

.....
.....
.....
.....
.....
.....
.....

- 97 difficult to answer
- 98 refuse to answer

**F3. Was the deceased in regular paid employment at the time of death?**

*Please circle the single most appropriate answer.*

- 1 yes ⇒go to F7
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**F4. Was he...**

*Please circle all answers which apply*

- 1 in irregular paid work
- 2 unemployed, seeking work
- 3 student ⇒go to F6
- 4 retired, except for retirement due to invalidity ⇒go to F6
- 5 retired due to invalidity ⇒go to F6
- 6 unemployed, not seeking work
- 9 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**F5. What was the main reason for him ceasing regular paid employment?**

*Please circle the single most appropriate answer.*

- 1 could not find a job after finishing education
- 2 was made redundant
- 3 a temporary job ended
- 4 was fired
- 5 gave up voluntarily due to unsatisfactory work salary/work conditions
- 6 gave up work because of ill health
- 8 gave up my job for other reasons (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**F6. How long before death did he cease regular paid employment?**

*Please circle the single most appropriate answer.*

- 1 had never been in regular paid employment ⇒go to F11
- 2 within the week before death
- 3 more than 1 week but less than 1 month before death
- 4 more than 1 month but less than 6 months before death
- 5 more than 6 months but less than 1 year before death
- 6 over 1 year before death )
- 97 difficult to answer ) ⇒go to F11
- 98 refuse to answer )

**I would now like to ask you some questions about the deceased's main occupation during the year before death**

**F7. What was the deceased's main occupation during the year before death?**

*Please answer in your own words.*

1

.....
.....
.....
.....

- 97 difficult to answer
- 98 refuse to answer

**F8. What was his main occupational status during the year before death?**

*Please circle the single most appropriate answer.*

- 1 Senior official or office top manager
- 2 Manager of department of branch office
- 3 Production and operation department manager
- 4 Physical and engineering science associate professional
- 5 Life science and health associate professional
- 6 Office clerk without higher education
- 7 Skilled worker
- 8 Unskilled worker
- 9 Entrepreneur
- 10 Other
- 97 difficult to answer
- 98 refuse to answer

*Interviewer! If there are any discrepancies between the respondent's occupational status and education, select the response for A15 according to occupational status. For example, a nurse with higher education is marked as 'office clerk without higher education', point '6, and a primary school teacher with secondary special education is marked as 'life science and health associate professional', point '5', etc. '*

**F9. What type of firm or organisation did he mainly work for during the year before death?**

*Please circle the single most appropriate answer.*

- 1 State/local enterprise/authority
- 2 Cooperative/employee owned firm
- 3 A private company
- 4 Joint state and private ownership
- 5 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**F10. In what branch of industry did he mainly work during the year before death?**

*Please circle the single most appropriate answer.*

- 1 civil service
- 2 education, culture and media
- 3 banks or other financial institutions
- 4 healthcare or social services
- 5 service industry
- 6 agriculture
- 7 industry, construction
- 8 transport, communications
- 9 military/police
- 10 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer



**F11. At the time of death, did he have any source of income (if he was in regular paid employment, exclude earnings from his main workplace)?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to F13
- 98 refuse to answer )

**F12. What were these sources of extra income?**

*Multiple responses are permitted. Please circle all that apply.*

- 1 Pension (any kind)
- 2 Occasional/irregular work
- 3 Social benefits (any kind)
- 4 Private enterprise
- 5 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**F13. Did his family produce agricultural products from a plot of land of which they had use?**

*Please circle the single most appropriate answer.*

- 1 did not have a plot of land
- 2 yes
- 3 no
- 97 difficult to answer
- 98 refuse to answer

**F14. Was he ever in the army?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to F17
- 98 refuse to answer )

**F15. What was his rank in the army?**

*Please circle the single most appropriate answer.*

- 1 private soldier
- 2 sergeant
- 3 warrant officer
- 4 officer
- 97 difficult to answer
- 98 refuse to answer

**F16. Did he ever serve in a zone of conflict?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**F17. Had he ever been in any kind of prison?**

*Please circle the single most appropriate answer.*

- 1 yes, during the previous year
- 2 yes, between 1 - 5 years ago
- 3 yes, more than 5 years ago
- 4 no, never
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you some further questions about the life of the deceased during the past 5 years

**G1 - G8: Did the deceased experience any of the following events in the 5 years before death? If so, when?**

	no	yes, in 12 months prior to death	yes, 1-2 years prior to death	yes, 2-5 years prior to death	Difficult to answer	Refuse to answer
G1 serious illness of wife/partner	1	2	3	4	97	98
G2 serious illness of other close family member or friend	1	2	3	4	97	98
G3 death of wife/partner	1	2	3	4	97	98
G4 death of other close family member or friend	1	2	3	4	97	98
G5 divorce/separation from wife/partner	1	2	3	4	97	98
G6 serious financial problems	1	2	3	4	97	98
G7 other serious problems involving family or friends	1	2	3	4	97	98
G8 serious work or employment-related problems	1	2	3	4	97	98

**G9. What were his relations with his family?**

*Please circle the single most appropriate answer.*

- 1 harmonious, peaceful
- 2 occasional quarrels and conflicts
- 3 frequent quarrels and conflicts
- 97 difficult to answer
- 98 refuse to answer

**G10. Did he confide in family members or friends about personal matters?**

*Please circle the single most appropriate answer.*

- 1 yes
  - 2 no
  - 97 difficult to answer
  - 98 refuse to answer
- )  
) ⇒ go to H1  
)

**G11. How often did he have contact with the people in which he confided?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 every week
- 3 every month
- 4 less than once a month
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you some questions concerning the circumstances surrounding the death

**H1. Were you with *the deceased* when he died?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**H2. Did he die in Izhevsk**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**H3. Can you tell me where *the deceased* died? Was it...**

*Please circle the single most appropriate answer.*

- 1 at home ⇒go to H5
- 2 in a hospital/medical facility ⇒go to H4
- 3 in a dacha )
- 4 in a friend's or family member's home )
- 5 at work )
- 6 in a public place )⇒go to H5
- 7 other (specify) ..... )
- 97 difficult to answer )
- 98 refuse to answer )

**H4. How long before the death was *the deceased* admitted to hospital?**

*Please circle the single most appropriate answer.*

- 1 the day before
- 2 up to a week before
- 3 longer than 1 week but less than 1 month before
- 4 longer than a month before
- 97 difficult to answer
- 98 refuse to answer

**H5. In your opinion, was the death expected or unexpected?**

*Please circle the single most appropriate answer.*

- 1 it was expected
- 2 it was sudden and unexpected
- 97 difficult to answer
- 98 refuse to answer

**H6. In your opinion, was the death due to natural causes or other causes?**

*Please circle the single most appropriate answer.*

- 1 it was due to disease
- 2 it was due to homicide )
- 3 it was due to suicide )
- 4 it was due to due to accidental injury )
- 5 It was due to poisoning by alcohol or other spirits ) ⇒ go to H10
- 6 it was due to other accidental cause (including drowning) )
- 97 difficult to answer )
- 98 refuse to answer )

**H7. Was this disease diagnosed by a doctor?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to H10
- 98 refuse to answer )

**H8. ...and what was it?**

*Please circle the single most appropriate answer.*

- 1 cancer
- 2 heart disease
- 3 hypertension/high blood pressure
- 4 diabetes
- 5 tuberculosis
- 6 hepatitis
- 8 stroke (cerebrovascular disease)
- 9 alcohol dependency or abuse
- 16 Other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**H9. When was it first diagnosed?**

*Please circle the single most appropriate answer.*

- 1 after the person died
- 2 within the last 6 months before the death
- 3 6 - 12 months before the death
- 4 1-5 years ago before the death
- 5 more than 5 years before the death
- 97 difficult to answer
- 98 refuse to answer

**H10. Were you the person who registered the death with the funeral service or ZAGS?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you about any diseases or disabilities that *the deceased* had

**J1. Did *the deceased* have any doctor diagnosed diseases which have long-term consequences for health, other than any you have already mentioned as having caused the death?**

*Please circle the single most appropriate answer.*

- 1    yes
- 2    no                                     )
- 97   difficult to answer                 ) ⇒go to J3
- 98   refuse to answer                    )

**J2. What was/were the disease(s)?**

*Multiple responses are permitted. Please circle all that apply.*

- 1    cancer
- 2    heart disease
- 3    hypertension/high blood pressure
- 4    diabetes
- 5    tuberculosis
- 6    hepatitis
- 7    other infectious and parasitic diseases and their consequences
- 8    stroke (cerebrovascular disease)
- 9    alcohol dependency
- 10   depression
- 11   other psychiatric conditions
- 12   diseases of bones, joints, vertebrae and musculo-skeletal system
- 13   diseases of kidney
- 14   other diseases of genito-urinary system
- 15   diseases of stomach, intestine and other digestive organs
- 16   Other (specify) .....
- 97   difficult to answer
- 98   refuse to answer

**J3. During the year before death, was *the deceased* ever hospitalised other than around the time of death?**

*Please circle the single most appropriate answer.*

- 1    yes, once
- 2    yes, more than once
- 3    no                                     )
- 97   difficult to answer                 ) ⇒go to J5
- 98   refuse to answer                    )



**J4. What was the reason for being hospitalised? (describe all occurrences)**

*Please answer in your own words.*

1

.....
.....
.....
.....
.....
.....
.....

97 difficult to answer

98 refuse to answer

**J5. When did *the deceased* last visit the polyclinic?**

*Please circle the single most appropriate answer.*

1 within the last few days before death

2 1 week before death

3 more than 1 week but less than 1 month before death

4 more than 1 month but less than 6 months before death

5 more than 6 months but less than 1 year before death

6 over 1 year before death

97 difficult to answer

98 refuse to answer

**J6. Where is *the deceased's* medical card?**

*Please answer in your own words.*

1

.....
.....
.....
.....
.....
.....
.....

97 difficult to answer

98 refuse to answer

**J7. Please give the name and address of the last polyclinic he attended.**

*Please answer in your own words.*

1

.....
.....
.....
.....
.....
.....

97 difficult to answer

98 refuse to answer

**J8. If he was registered disabled at the time of death, how long before death was he registered?**

*Please circle the single most appropriate answer.*

- 1 not applicable ⇒ go to K1
- 2 within the 6 months before death
- 3 between 6 and 12 months before death
- 4 between 1 and 5 years before death
- 5 between 6 and 10 years before death
- 6 over 10 years before death but not his whole life
- 7 had always been disabled
- 97 difficult to answer
- 98 refuse to answer

**J9. What was the reason for being registered disabled?**

*Please circle the single most appropriate answer.*

- 1 he was disabled from birth
- 2 he was disabled from war
- 3 he was disabled due to disease
- 4 he was disabled due to occupational disease
- 5 he was disabled due to involvement in Chernobyl clear-up
- 6 he was disabled due to an accident at work
- 7 he was disabled due to other accidents
- 97 difficult to answer
- 98 refuse to answer

**J10. What was the nature of the disability? (please include the level of invalidity in your description)**

*Please answer in your own words.*

1

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97 difficult to answer

98 refuse to answer

I would now like to ask you some questions about the *deceased's* health during the year before his death

**K1. Had *the deceased* broken any bones during the year before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**K2. In the months preceding his death, did *the deceased* cough when he got up in the morning?**

*Please circle the single most appropriate answer.*

- 1 usually
- 2 sometimes
- 3 rarely
- 4 never
- 97 difficult to answer
- 98 refuse to answer

**K3. In the months preceding his death, could *the deceased* climb up a flight of stairs without becoming breathless?**

*Please circle the single most appropriate answer.*

- 1 yes, easily
- 2 yes, with some difficulty
- 3 no - too difficult
- 97 difficult to answer
- 98 refuse to answer

**K4. In the months preceding his death, how difficult was it for *the deceased* to walk about 1km?**

*Please circle the single most appropriate answer.*

- 1 not at all difficult
- 2 slightly difficult
- 3 very difficult/impossible
- 97 difficult to answer
- 98 refuse to answer

**K5. Did *the deceased* appear to have lost a significant amount of weight during the past year?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**K6. In the months preceding his death, was *the deceased* able to carry out his daily activities, such as shopping, washing or dressing, which a totally health person can manage without difficulty?**

*Please circle the single most appropriate answer.*

- 1 yes, up to when he died
- 2 no, not during the month before death
- 3 no, not during the 6 months before death
- 4 no, not for over 6 months before death
- 97 difficult to answer
- 98 refuse to answer

**K7. In the months preceding his death, did *the deceased* do physical exercise in his leisure time?**

*Please circle the single most appropriate answer.*

- 1 yes, several times a week or more
- 2 yes, sometimes, but less than several times a week
- 3 never )
- 97 difficult to answer ) ⇒ go to K9
- 98 refuse to answer )

**K8. What kind of exercise?**

*Please answer in your own words.*

1

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- 97 difficult to answer
- 98 refuse to answer

**K9. Did *the deceased* usually walk or cycle for more than 30 minutes per day?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**K10. Did *the deceased* have a job that involved regular physical activity?**

*Please circle the single most appropriate answer.*

- 1 yes, a lot of physical activity
- 2 yes, moderate physical activity
- 3 no, not much/no physical activity
- 4 not applicable
- 97 difficult to answer
- 98 refuse to answer

**K11 How tall was *the deceased*? Please answer as accurately as you can.**

cm

- 97 difficult to answer
- 98 refuse to answer

I am now going to ask you a series of questions regarding drinking of alcohol by the deceased. These questions are about the year prior to his death, unless otherwise specified

**L1-L4. For each type of drink listed in the left hand column, please indicate how often each was usually drunk**

	every day or more often	nearly every day	three or four times a week	once or twice a week	1-3 times a month	a few times per year	never or almost never	difficult to answer	refuse to answer
L1 beer	1	2	3	4	5	6	7	98	99
L2 wine	1	2	3	4	5	6	7	98	99
L3 spirits	1	2	3	4	5	6	7	98	99
L4 alcoholic substances NOT intended to be drunk	1	2	3	4	5	6	7	98	99

*Interviewer! If the respondent answered '7', '98' or '99' to ALL of the previous four questions, skip to L35*

**L5-L8. For each type of drink listed in the left hand column, please indicate on which day of the week each was usually drunk**

	only at the weekend	only on weekdays	any day	every day	only on holidays/celebration	never or almost never	difficult to answer	refuse to answer
L5 beer	1	2	3	4	5	6	98	99
L6 wine	1	2	3	4	5	6	98	99
L7 spirits	1	2	3	4	5	6	98	99
L8 alcoholic substances NOT intended to be drunk	1	2	3	4	5	6	98	99

**L9. How much beer did he usually drink on one occasion? ('occasion' means a single continuous period of drinking)**

*Please circle the single most appropriate answer.*

- 1 never drank beer
- 2 1 bottle or less
- 3 2-4 bottles
- 4 5-6 bottles
- 5 more than 6 bottles
- 97 difficult to answer
- 98 refuse to answer

**L10. How much wine did he usually drink on one occasion?**

*Please circle the single most appropriate answer.*

- 1 never drank wine
- 2 up to 200g
- 3 between 200 - 400g
- 4 between 400 - 600g
- 5 between 600 - 1000g
- 6 more than 1 litre
- 97 difficult to answer
- 98 refuse to answer

**L11. What quantity of spirits, such as vodka or other strong drinks, did he usually drink on one occasion?**

*Please circle the single most appropriate answer.*

- 1 never drank spirits
- 2 between 50 – 100g
- 3 between 100 - 200g
- 4 between 200 - 300g
- 5 between 300 - 400g
- 6 between 400 - 500g
- 7 more than 500g
- 97 difficult to answer
- 98 refuse to answer

**L12. What was the maximum quantity of beer ever drunk on one occasion?**

*Please circle the single most appropriate answer.*

- 1 never drank beer
- 2 1 bottle or less
- 3 2-4 bottles
- 4 5-6 bottles
- 5 more than 6 bottles
- 97 difficult to answer
- 98 refuse to answer



**L13. What was the maximum quantity of wine ever drunk on one occasion?**

*Please circle the single most appropriate answer.*

- 1 never drank wine
- 2 up to 200g
- 3 between 200 - 400g
- 4 between 400 - 600g
- 5 between 600 - 1000g
- 6 more than 1 litre
- 97 difficult to answer
- 98 refuse to answer

**L14. What was the maximum quantity of spirits ever drunk on one occasion?**

*Please circle the single most appropriate answer.*

- 1 never drank spirits
- 2 between 50 – 100g
- 3 between 100 - 200g
- 4 between 200 - 300g
- 5 between 300 - 400g
- 6 between 400 - 500g
- 7 more than 500g
- 97 difficult to answer
- 98 refuse to answer

**L15. Did he ever drink spirits together with either beer or wine at the same sitting?**

*Please circle the single most appropriate answer.*

- 1 yes, often
- 2 yes, sometimes
- 3 no, never
- 97 difficult to answer
- 98 refuse to answer

**L16. Did he ever drink large quantities of spirits without also eating some food at the same sitting?**

*Please circle the single most appropriate answer.*

- 1 always
- 2 sometimes
- 3 rarely/never
- 97 difficult to answer
- 98 refuse to answer

**L17. How often did he become excessively drunk?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 once a week
- 4 several times a month
- 5 once a month
- 6 less than once a month
- 7 never or almost never
- 97 difficult to answer
- 98 refuse to answer

**L18. Did he ever drink alcohol before noon?**

*Please circle the single most appropriate answer.*

- 1 no
- 2 yes, occasionally
- 3 yes, frequently
- 97 difficult to answer
- 98 refuse to answer

**L19. How often did he have a hangover?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 about once a week
- 4 several times a month
- 5 about once a month
- 6 less than once a month
- 7 never or almost never
- 97 difficult to answer
- 98 refuse to answer

**L20. How often did he fail to fulfil his work obligations due to drinking alcohol?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 about once a week
- 4 several times a month
- 5 about once a month
- 6 less than once a month
- 7 never
- 8 not applicable
- 97 difficult to answer
- 98 refuse to answer

**L21. How often did he fail to fulfil his family or personal obligations due to drinking alcohol?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 about once a week
- 4 several times a month
- 5 about once a month
- 6 less than once a month
- 7 never
- 97 difficult to answer
- 98 refuse to answer

**L22. Did he ever go to sleep at night with his clothes on because of being drunk?**

*Please circle the single most appropriate answer.*

- 1 every day
- 2 several times a week
- 3 about once a week
- 4 several times a month
- 5 about once a month
- 6 less than once a month
- 7 never or almost never
- 97 difficult to answer
- 98 refuse to answer

**L23. Did he ever drink alone?**

*Please circle the single most appropriate answer.*

- 1 yes, often
- 2 yes, sometimes
- 3 no, never
- 97 difficult to answer
- 98 refuse to answer

**L24. Did he usually drink alcohol at home or in other places?**

*Please circle the single most appropriate answer.*

- 1 usually at home
- 2 sometimes at home, sometimes elsewhere
- 3 usually elsewhere
- 97 difficult to answer
- 98 refuse to answer

I would now like to ask you about episodes of 'zapoï' in the deceased's life. By 'zapoï', I mean a continuous drunkenness of several days or more during which the person does not work and is withdrawn from normal life

**L25. Did he have one or more episodes of zapoï in the year before death?**

*Please circle the single most appropriate answer.*

- 1 yes, often
- 2 yes, sometimes
- 3 no, never )
- 97 difficult to answer ) ⇒ go to L32
- 98 refuse to answer )

**L26. Did he have one or more episodes of zapoï in the month before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to L32
- 98 refuse to answer )

**L27. Did he have one or more episodes of zapoï in the week before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to L32
- 98 refuse to answer )

**L28. During his most recent episode of heavy drinking, what was the maximum quantity of beer drunk?**

*Please circle the single most appropriate answer.*

- 1 none
- 2 1 bottle or less
- 3 2-4 bottles
- 4 5-6 bottles
- 5 more than 6 bottles
- 6 drank beer, but not sure of the quantity
- 97 difficult to answer
- 98 refuse to answer

**L29. During his most recent episode of heavy drinking, what was the maximum quantity of wine drunk?**

*Please circle the single most appropriate answer.*

- 1 none
- 2 up to 200g
- 3 between 200 - 400g
- 4 between 400 - 600g
- 5 between 600 - 1000g
- 6 more than 1 litre
- 7 drank wine, but not sure of the quantity
- 97 difficult to answer
- 98 refuse to answer

**L30. During his most recent episode of heavy drinking, what was the maximum quantity of spirits drunk?**

*Please circle the single most appropriate answer.*

- 1 none
- 2 between 50 – 100g
- 3 between 100 - 200g
- 4 between 200 - 300g
- 5 between 300 - 400g
- 6 between 400 - 500g
- 7 more than 500g
- 8 drank spirits, but not sure of the quantity
- 97 difficult to answer
- 98 refuse to answer

**L31. During his most recent episode of zapoi, did he drink any other alcoholic substances other than those intended as drinks?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**L32. Had he been arrested because he was drunk during the year before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**L33. Around the time of his death, was he drinking more than, less than, or about the same as he had been one year previously?**

*Please circle the single most appropriate answer.*

- 1 more than a year before
- 2 about the same as a year before
- 3 less than a year before
- 97 difficult to answer
- 98 refuse to answer

**L34. Around the time of his death, was he drinking more than, less than, or about the same as he had been one month previously?**

*Please circle the single most appropriate answer.*

- 1 more than a month before
- 2 about the same as a month before
- 3 less than a month before
- 97 difficult to answer
- 98 refuse to answer

**L35. Was there ever any period in his life when he drank heavily other than during the 12 months before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**L36. Had he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to L38
- 98 refuse to answer )

**L37. Did he get such help or advice in the year before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**L38. Had he ever been taken to a sobering-up centre?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no )
- 97 difficult to answer ) ⇒ go to L40
- 98 refuse to answer )

**L39. Was this during the year before death?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 97 difficult to answer
- 98 refuse to answer

**L40. Do you believe that the death of the deceased was in any way related to his drinking of alcohol?**

*Please circle the single most appropriate answer.*

- 1 yes
- 2 no
- 3 possibly
- 97 difficult to answer
- 98 refuse to answer

I will now ask you some questions concerning *the deceased's* smoking habits

**M1. Was he a current smoker at the time of death?**

*Please circle the single most appropriate answer.*

- 1 never a smoker ⇒ go to M6
- 2 no, ex-smoker
- 3 yes, a current-smoker ⇒ go to M3
- 97 difficult to answer ⇒ go to M6
- 98 refuse to answer ⇒ go to M6

**M2. How many years ago did he stop smoking regularly?**

*Please circle the single most appropriate answer.*

- 1 less than one year before death
- 2 more than 1 year but less than 5 years before death
- 3 more than 5 years but less than 10 years before death
- 4 more than 10 years before death
- 97 difficult to answer
- 98 refuse to answer

**M3. What did he smoke most often?**

*Please circle the single most appropriate answer.*

- 1 papyrosi
- 2 filtered cigarettes
- 3 unfiltered cigarettes
- 4 other (specify) .....
- 97 difficult to answer
- 98 refuse to answer

**M4. When he smoked, how many per day was usual?**

*Please circle the single most appropriate answer.*

- 1 1-5 per day
- 2 6-10 per day
- 3 11-20 per day
- 4 more than 20 per day
- 97 difficult to answer
- 98 refuse to answer



**M5. How old was he when he started smoking regularly?**

*Please circle the single most appropriate answer.*

- 1 <10 years old
- 2 10-19 years old
- 3 20-29 years old
- 4 >30 years old
- 97 difficult to answer
- 98 refuse to answer

**M6. Have his parents ever smoked?**

*Please circle the single most appropriate answer.*

- 1 yes, father only
- 2 yes, mother only
- 3 yes, both parents
- 4 no, neither
- 97 difficult to answer
- 98 refuse to answer

**Thank you for your time in helping us with this study**

The following questions are answered only by you as an interviewer and are not to be read out. Question X1 is deliberately excluded:

**X2** How would you judge the reliability of the answers from this interview?

- 1 satisfactory
- 2 not entirely satisfactory. For example, a moderate level of non-response by the subject, or perhaps small interruptions affected the quality of the responses
- 3 poor. For example, a high level of non-response by the subject, or perhaps many/constant interruptions affected the quality of the responses.

**X3** Were there any other people present in the same room while the interview was taking place?

- 1 yes
- 2 no ⇒ go to X5

**X4.** Please provide details of other people present during the interview, including their relationship to respondent:

1

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.....
.....

**X5.** Were there any interruptions to the interview?

- 1 yes
- 2 no ⇒ go to X7

**X6.** Please provide details of interruptions, including their duration:

1

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**X7.** Any other comments, including indication of questions that were particularly hard to answer

1

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**End of questionnaire**

## **Appendix 4**

**Index-proxy agreement: kappa analyses performed  
using pilot data**

Q	Question text	Comparison strata	weighted kappa	n			Comments		
				case proxy	control proxy	control			
C1	how many people currently live in this household		1.00	5	0	0	5		
				15	7	7	29		
				29	16	14	59		
				15	27	27	69		
				5	15	14	34		
				2	2	2	6		
				1	0	0	1		
				0	2	2	4		
				1	0	0	1		
				0	(0.00%)	0	(0.00%)	0	(0.00%)
0	(0.00%)	0	(0.00%)	0	(0.00%)				
C2	how many people including the subject, lived in this household at the time of death		not calculate d	6			6		
				16			16		
				28			28		
				14			14		
				5			5		
				2			2		
				1			1		
				1			1		
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
C3	have any new people moved in or out of the house since the deceased died	yes no	not calculate d	6	0	0	6		
				67	0	0	67		
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
C5	what kind of residence is this	hostel shared/communal flat flat, sole use part of shared house house, sole use other	1.00	2	0	1	3		
				2	4	3	9		
				57	56	52	165		
				5	0	0	5		
				7	9	9	25		
				0	0	0	0		
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)
				0	(0.00%)	0	(0.00%)	0	(0.00%)

Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 for all groups.

These questions were only asked of case proxies, therefore kappa could not be calculated. Non response is 0 for all groups.

Kappa is 1 indicating extremely good inter-observer agreement.

Q	Question text	Comparison strata	weighted kappa	n				Comments			
				case proxy	control proxy	control	total				
C6	what type of building is this	wooden house	0.95	12	8	8	28				
		dacha or garden house		27	22	20	69				
		country yard		33	36	35	104				
		cottage		1	3	3	7				
		other		0	0	0	0				
		97, 98 (don't know/refuse to ans)		0	(0.00%)	0	(0.00%)		0	(0.00%)	
C7	who is the owner of this dwelling	99 (system generated skip)	0.94	0	(0.00%)	0	(0.00%)				
		a member of the household the state or municipality someone who lives elsewhere other		33	34	28	95				
		97, 98 (don't know/refuse to ans)		36	34	35	105				
		99 (system generated skip)		1	1	1	3				
		other		0	0	0	0				
		97, 98 (don't know/refuse to ans)		3	(4.11%)	0	(0.00%)		2	(3.03%)	5
C8	how did a member or members of this household come to own this dwelling	99 (system generated skip)	0.88	0	(0.00%)	0	(0.00%)				
		built it		3	1	2	6				
		purchased it		5	4	5	14				
		obtained it through privatisation		16	23	17	56				
		inherited it/was a gift		4	4	2	10				
		exchanged with diff. household		3	0	0	3				
		exchanged, and added own money		1	2	2	5				
		other		0	0	0	0				
		97, 98 (don't know/refuse to ans)		1	(3.03%)	0	(0.00%)	2	(6.67%)	3	(3.03%)
		99 (system generated skip)		40	(54.79%)	35	(50.72%)	36	(54.55%)	111	(53.37%)
C9	how many rooms are there in this residence in total	1	0.97	12	9	7	28				
		2		29	31	30	90				
		3		21	19	19	59				
		4		8	9	9	26				
		5		2	0	0	2				
		6		1	1	1	3				
		97, 98 (don't know/refuse to ans)		0	(0.00%)	0	(0.00%)	0	(0.00%)	0	(0.00%)
		99 (system generated skip)		0	(0.00%)	0	(0.00%)	0	(0.00%)	0	(0.00%)

For all these questions, kappa is extremely high indicating very good inter-observer agreement. Non response is low for all groups, except for a slight increase in non-response among proxies for question C8. However, the level of non-response is still low even here.

Q	Question text	Comparison strata	weighted happ	n				Comments
				case proxy	control proxy	control	total	
C10	how many rooms are used for sleeping in this residence.		0.98	16	12	10	38	
				37	40	40	117	
				17	12	12	41	
				2	5	4	11	
				1	0	0	1	
	97, 98 (don't know/refuse to ans)			0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	
	99 (system generated skip)			0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	
C11	how many utility rooms are there in this residence in total		0.89	3	4	4	11	
				7	4	4	15	
				10	9	9	28	
				7	8	5	20	
				25	26	27	78	
				17	17	16	50	
				2	1	1	4	
				2	0	0	2	
					97, 98 (don't know/refuse to ans)			0 (0.00%)
	99 (system generated skip)			0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	

Q	Question text	Comparison strata	weighted kappa	n				Comments
				case proxy	control proxy	control	total	
C12	does this household have access to...	comfortable toilet	1.00	61	60	57	178	Kappa is extremely high for all these questions indicating very good inter-observer agreement. Kappa could not be calculated for 'electricity' as there were too few rating categories.
		no		12	9	9	30	
		hot water supplied	1.00	56	55	53	164	
		no		17	14	13	44	
		cold water supplied	1.00	63	61	58	182	
		no		10	8	8	26	
		central heating	1.00	62	60	57	179	
		no		11	9	9	29	
		gas supply	1.00	57	59	55	171	
		no		16	10	11	37	
		telephone	0.96	46	52	50	148	
		no		27	17	16	60	
		electricity	-	72	67	66	205	
no		1	2	0	3			
C13	does this household entirely or partly use or own...	wooden house	0.65	4	3	3	10	As per C12. Kappa could not be calculated for 'cottage' or 'place for enterprise' as there were too few rating categories. Kappa was 0 for 'additional flat, room or house' indicating no inter-observer agreement using these data.
		no		69	66	63	198	
		a dacha or garden house	0.91	30	37	33	100	
		no		43	32	33	108	
		a country yard	0.88	26	37	35	98	
		no		47	32	31	110	
		a cottage	-	0	0	0	0	
		no		73	69	66	208	
		additional flat, room or house	0.00	4	3	0	7	
		no		69	66	66	201	
		place for enterprise	-	0	0	0	0	
		no		73	69	66	208	
		none of the above	0.87	31	21	25	77	
no		42	48	41	131			

Q	Question text	Comparison strata	weighted kappa	n				Comments
				case proxy	control proxy	control	total	
C14	which of the following possessions does this household own	car	1.00	20	28	26	74	All these questions have high kappas, indicating very good inter-observer agreement.
		no	53	41	40	134		
		motorcycle	0.92	5	8	9	22	
		no	68	61	57	186		
		livestock	0.85	0	4	3	7	
		no	73	65	63	201		
		modern television	0.84	54	59	60	173	
		no	19	10	6	35		
		video	0.91	30	29	31	90	
		no	43	40	35	118		
		videocamera	1.00	0	5	5	10	
		no	73	64	61	198		
		computer	1.00	4	17	16	37	
		no	69	52	50	171		
		modern washing machine	0.83	23	17	15	55	
		no	50	52	51	153		
		microwave	1.00	7	6	6	19	
		no	66	63	60	189		
		telephone	1.00	44	51	49	144	
		no	29	18	17	64		
hifi	0.83	14	15	17	46			
no	59	54	49	162				
fridge	0.79	66	65	64	195			
no	7	4	2	13				
none of the above	1.00	5	1	1	7			
no	68	68	65	201				



Q	Question text	Comparison strata	weighted kappa	n				Comments
				case proxy	control proxy	control	total	
C15	on what kind of income did this household rely on during the past year	regular salaries	0.48	61	67	64	192	Kappa is high for most categories in this question except for 'regular salaries' which had only moderate inter-observer agreement, and 'income from bank interest or dividends' which showed no agreement. No kappa was obtained for 'welfare: death of only breadwinner' or 'none' due to lack of responses, and no kappa was obtained for 'welfare: social benefits' due to insufficient rating categories.
		no		2	2		16	
		occasional salaries	1.00	10	7	7	24	
		no		63	62	59	184	
		income/revenue from business	0.65	4	2	4	10	
		no		69	67	62	198	
		income/revenue from agriculture	0.66	1	1	2	4	
		no		72	68	64	204	
		income from bank interest or dividends	0.00	1	0	2	3	
		no		72	69	64	205	
		age pensions	0.87	14	15	15	44	
		no		59	54	51	164	
		invalidity pensions	0.95	18	12	11	41	
		no		55	57	55	167	
		welfare: death of only breadwinner	-	0	0	0	0	
		no		73	69	66	208	
		welfare: social benefits	-	4	5	5	14	
		no		69	64	61	194	
		welfare: child benefit	0.85	27	19	19	65	
		no		46	50	47	143	
scholarships	1.00	5	4	3	12			
no		68	65	63	196			
help of relatives	0.65	5	3	3	11			
no		68	66	63	197			
other	0.66	0	2	1	3			
no		73	67	65	205			
none	-	0	0	0	0			
no		73	69	66	208			

Q	Question text	Comparison strata	weighted kappa	N				total	Comments
				case proxy	control proxy	control			
C16	did the subject regularly contribute to the household income during the past few months	yes no 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.73	47	64	61	172	Kappa is high, indicating good inter-observer agreement. Non-response is low for all groups.	
				25	4	5	34		
				1 (1.37%)	1 (1.45%)	0 (0.00%)	2 (0.96%)		
C17	what proportion of the household's income was normally spent on food during the past year	less than half about half more than half 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.50	3	7	6	16	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is slightly higher among proxies than for controls. Overall, this question appears to be performing reasonably well.	
				20	15	15	50		
				47	47	41	135		
C18	how do you think the economic situation of the household changed during the past year	improved a lot improved a little remained the same got a little worse got a lot worse 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.38	3 (4.11%)	0 (0.00%)	4 (6.06%)	7 (3.37%)	Kappa is quite low for this question indicating poor inter-observer agreement. Non-response is 0 for all groups.	
				0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		
				4	1	0	5		
C19	which of the phrases best describes the household's financial situation during the year before death	not able to purchase basic necessities able to purchase basic necessities able to occasionally purchase expensive goods able to purchase everything there was money for everything 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.47	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is low for all groups.	
				0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		
				17	11	9	37		
C19	which of the phrases best describes the household's financial situation during the year before death	not able to purchase basic necessities able to purchase basic necessities able to occasionally purchase expensive goods able to purchase everything there was money for everything 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.47	41	48	42	131	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is low for all groups.	
				9	6	11	26		
				3	2	3	8		
C19	which of the phrases best describes the household's financial situation during the year before death	not able to purchase basic necessities able to purchase basic necessities able to occasionally purchase expensive goods able to purchase everything there was money for everything 97, 98 (don't know/refuse to ans) 99 (system generated skip)	0.47	2	1	0	3	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is low for all groups.	
				1 (1.37%)	1 (1.45%)	0 (0.00%)	2 (0.97%)		
				0 (0.00%)	0 (0.00%)	1 (1.52%)	1 (0.48%)		

Q	Question text	Comparison strata	series code	Control proxy		Control		weighted kappa	n			Comments						
				OR	95% CI	OR	95% CI		case proxy	control proxy	control		total					
D1	Is the subject's mother alive	yes no 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00	-	1.00	-	1.00	38	50	48	136	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is very low in all groups. The odds ratios are quite high suggesting that this question is reasonably predictive.					
				(ref)		(ref)		(0.00%)	(1.45%)	0	(0.00%)	1		(0.40%)				
				2.56	1.23, 5.30	2.46	1.18, 5.09	0	(0.00%)	0	(0.00%)	0		(0.00%)				
								0	(0.00%)	0	(0.00%)	0		(0.00%)				
D2	When did his mother die	within the last year 1 - 5 years ago 6-10 years ago more than 10 years ago 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1) c(3,1) c(4,1)	1.00	-	1.00	-	0.90	1	3	2	6	Kappa is very high indicating good inter-observer agreement. The observed trend of a peak in ORs for the third strata is probably not robust but rather an artefact of the data explained by the low number of responses in that strata. However, it is apparent that this question has some predictive value. No response is quite high which is not unexpected for a question of this nature.					
				(ref)		(ref)				12	3	4		19				
				12.00	0.57, 251.13	6.00	0.34, 107.42	7	(2.86%)	1	(5.26%)	1		(4.17%)				
				21.00	0.34, 1301.30	14.00	0.26, 745.90	14	(52.05%)	50	(72.46%)	48		(72.73%)				
D3	How old was his mother when she died	gave answer between 35 - 87 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1	-	-	-	-	0.87	24	17	17	58	Kappa, based on the actual age, is high indicating that this question is answered well when it is answered. However, there is quite a high non-response rate, indicating that often this question cannot be answered by proxies.					
										11	(31.43%)	2		(10.53%)	1	(5.56%)	14	(19.44%)
								38	(52.05%)	50	(72.46%)	48		(72.73%)	136	(65.38%)		

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments						
				OR	95% CI	OR	95% CI		case proxy	control proxy	control		total					
D4	Is the subject's father alive	yes	1	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00	19	26	27	72	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is reasonably low in all groups, although higher than the comparable question for mothers. The odds ratios are not particularly high, suggesting that this question is only slightly predictive.					
		no	c(2,1)	1.87	0.90, 3.91	2.11	1.01, 4.43		52	38	35	125						
D5	When did his father die	97, 98 (don't know/refuse to ans)							2	(2.74%)	5	(7.25%)	4	(6.06%)	11	(5.29%)	Kappa is very high indicating good inter-observer agreement. ORs were not obtained as there were 0 responses in the baseline category for cases. Looking at the number of responses alone, it appears that this question may be predictive, especially in the higher strata. Non-response is quite high which is not unexpected for a question of this nature.	
		99 (system generated skip)						0	(0.00%)	0	(0.00%)	0	(0.00%)	0	(0.00%)	0		(0.00%)
		within the last year	1	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	0.86	0	1	1	1	2					
		1 - 5 years ago	c(2,1)	.	.	.	.		6	7	6	19						
		6-10 years ago	c(3,1)	.	.	.	.		8	4	5	17						
D6	How old was his father when he died	more than 10 years ago	c(4,1)	.	.	.	.		35	22	22	79						
		97, 98 (don't know/refuse to ans)						5	(9.26%)	9	(20.93%)	5	(12.82%)	19	(13.97%)			
		99 (system generated skip)						19	(26.03%)	26	(37.68%)	27	(40.91%)	72	(34.62%)			
D6	How old was his father when he died	gave answer between 24 and 86	1	-	-	-	-	0.91	37	29	32	98	Kappa, based on the actual age, is high indicating that this question is answered well when it is answered. However, there is quite a high non-response rate, indicating that often this question cannot be answered by proxies.					
		97, 98 (don't know/refuse to ans)						17	(23.29%)	14	(20.29%)	7		(10.61%)	38	(18.27%)		
		99 (system generated skip)						19	(26.03%)	16	(27.12%)	27	(40.91%)	72	(34.62%)			

Q	Question text	Comparison strata	kappa	n				Comments
				case proxy	control proxy	control	total	
E11	which region was the subject born in	Izhevsk	0.98	36	34	33	103	Kappa is very high indicating extremely good inter-observer agreement. Non-response is very low in all groups.
		other part of Udmurtia different oblast of Russia part of former Soviet Union outside Russia outside former Soviet Union		19	19	18	56	
E12	was the place he was born in an urban or rural area	97, 98 (don't know/refuse to ans)	(not weighted)	1	0	0	1	Kappa is very high indicating extremely good inter-observer agreement. Non-response is very low in all groups.
		99 (system generated skip)		0	0	0	0	
E13	how long had he continuously lived in Izhevsk	urban	0.90	6	8	7	21	Kappa is very high indicating extremely good inter-observer agreement. Non-response is very low in all groups.
		rural		30	27	26	83	
E14	what is his marital status	97, 98 (don't know/refuse to ans)	(not weighted)	1	0	0	1	Kappa is based on year provided in answer. Its value is very high, indicating good inter-observer agreement. Non-response is higher in proxies than controls, indicating that this question is more difficult for proxies to answer than the subject themselves.
		99 (system generated skip)		36	34	33	103	
E14	what is his marital status	since birth	0.87	34	35	33	102	Kappa is based on year provided in answer. Its value is very high, indicating good inter-observer agreement. Non-response is higher in proxies than controls, indicating that this question is more difficult for proxies to answer than the subject themselves.
		gave a year between 1953 and 1996		35	29	33	97	
E14	what is his marital status	97, 98 (don't know/refuse to ans)	(weighted)	4	5	0	9	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 in all groups.
		99 (system generated skip)		0	0	0	0	
E14	what is his marital status	living together with spouse in registered marriage	1.00	44	51	48	143	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 in all groups.
		living together with spouse but not in a registered marriage		9	4	4	17	
E14	what is his marital status	divorced or separated	(not weighted)	10	7	7	24	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 in all groups.
		widower		1	1	1	3	
E14	what is his marital status	never married	(not weighted)	9	6	6	21	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 in all groups.
		97, 98 (don't know/refuse to ans)		0	0	0	0	
E14	what is his marital status	99 (system generated skip)	(not weighted)	0	0	0	0	Kappa is 1 indicating extremely good inter-observer agreement. Non-response is 0 in all groups.
		99 (system generated skip)		0	0	0	0	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments		
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total			
F1	what is his level of education	incomplete secondary	1	1.00 (ref)	.	1.00 (ref)	.	0.87	12	6	5	23	Kappa is high indicating good inter-observer agreement. It is difficult to identify a clear trend from these data - it may be a binomial effect, or approaching a linear trend. More data is required to determine the pattern. However, it is clear that this question is quite predictive. Non-response is very low in all groups.		
		complete secondary	c(2,1)	0.52	0.16, 1.67	0.38	0.11, 1.30		23	22	25	70			
		professional school	c(3,1)	0.65	0.18, 2.39	0.68	0.17, 2.72		13	10	8	31			
		specialised secondary	c(4,1)	0.47	0.14, 1.59	0.42	0.12, 1.50		17	18	17	52			
		incomplete higher	c(5,1)	.	.	0.00	.		0	0	1	1			
		higher	c(6,1)	0.23	0.05, 1.02	0.25	0.05, 1.20		6	13	10	29			
		97, 98 (don't know/refuse to ans)							2	(2.74%)	0	(0.00%)		2	(0.96%)
F3	is he in regular paid employment	yes	1	1.00 (ref)	.	1.00 (ref)	.	0.96	33	53	49	135	Kappa is high indicating good inter-observer agreement. The ORs are high and significant, indicating that this question is predictive. Non-response is 0 in all groups.		
		no	c(2,1)	4.02	1.86, 8.66	3.49	1.64, 7.43		40	16	17	73			
		97, 98 (don't know/refuse to ans)							0	(0.00%)	0	(0.00%)		0	(0.00%)
		99 (system generated skip)							0	(0.00%)	0	(0.00%)		0	(0.00%)
F4	was he...	in irregular paid work	1	1.00 (ref)	.	1.00 (ref)	.	0.80	6	5	6	17	Where obtained, the kappas are extremely high. For two categories, 0 responses were obtained. These categories may be superfluous. OR for 'unemployed, seeking work and 'retired due to invalidity' are quite high, indicating that these categories are quite predictive. 'Retired due to reasons other than invalidity' appears to be protective. 'in irregular paid work' has ORs close to 0, indicating that this category is not predictive.		
		no	c(1,0)	1.15	0.33, 3.96	0.90	0.27, 2.34		67	64	60	191			
		unemployed, seeking work	1	1.00 (ref)	.	1.00 (ref)	.	1.00	8	3	3	14			
		no	c(1,0)	2.71	0.68, 10.83	2.58	0.65, 10.34		65	66	63	194			
		student	1	1.00 (ref)	.	1.00 (ref)	.	-	0	0	0	0			
		no	c(1,0)	.	.	.	.		73	69	66	208			
		retired, except if due to invalidity	1	1.00 (ref)	0.00, 0.00	1.00 (ref)	.	1.00	1	3	3	7			
		no	c(1,0)	0.31	0.03, 3.06	0.29	0.03, 2.93		72	66	63	201			
		retired due to invalidity	1	1.00 (ref)	.	1.00 (ref)	.	1.00	18	7	7	32			
		no	c(1,0)	2.90	1.10, 7.62	2.76	1.05, 7.25		55	62	59	176			
other specify)	1	1.00 (ref)	.	1.00 (ref)	.	-	6	0	0	6					
no	c(1,0)	.	.	.	.		67	69	66	202					

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
F5	how long did ago did he cease regular paid employment	In last week 1-4 weeks ago 1-6 months ago 6 months - 1 year ago over 1 year ago	2 c(3,2) c(4,2) c(5,2) c(6,2)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	0.81	0	0	0	0	No ORs were obtained due to lack of response in the baseline category. However, kappa was very high indicating good inter-observer agreement, and non-response was 0 in all groups.
				.	.	.	.	0	1	1	2		
				.	.	.	.	1	2	2	5		
				.	.	.	.	5	0	0	5		
				.	.	.	.	13	1	2	16		
				0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		
F6	what was the main reason for ceasing regular paid employment	97, 98 (don't know/refuse to ans) 99 (system generated skip) could not find a job after finishing education enterprise/organisation was closed or reduced temporary job ended was fired gave up work because of ill health gave up for other reasons	1 c(2,1) c(3,1) c(4,1) c(5,1) c(6,1)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	-	0	0	0	0	There were very few responses to this question - over 75% of respondents did not answer. However, non-response was higher in controls showing that there is some heterogeneity between cases and controls for this question. Due to the low number of responses, neither ORs nor kappas could be obtained.
				.	.	.	.	1	0	0	1		
				.	.	.	.	0	0	0	0		
				.	.	.	.	6	1	1	8		
				.	.	.	.	6	0	0	6		
				0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	1 (7.14%)	0 (0.00%)	0 (0.00%)	1 (6.25%)		
F11	does he have any other source of income other than regular paid employment	97, 98 (don't know/refuse to ans) 99 (system generated skip) yes no	1 c(2,1)	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)	0.86	13	8	9	30	Kappa is high indicating good inter-observer agreement. The ORs are reduced although not significant. This question may have some predictive value. Non-response is slightly higher in probes than for the control, but low in all groups.
				0.62	0.24, 1.61	0.70	0.28, 1.79	58	58	57	173		
				2 (2.74%)	2 (2.94%)	0 (0.00%)	4 (1.93%)	0	0	0	0		
				0 (0.00%)	1 (1.45%)	0 (0.00%)	1 (0.48%)	0	1	0	1		
				51 (72.86%)	63 (94.03%)	59 (92.19%)	173 (86.07%)	54 (79.41%)	65 (98.48%)	61 (98.39%)	180 (91.84%)		
				0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	1 (7.14%)	0 (0.00%)	0 (0.00%)	1 (6.25%)		

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments	
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total		
F14	was he ever in the army	yes, as a soldier	1	1.00 (ref)	.	1.00 (ref)	.	0.91	29	27	24	80	Kappa is very high indicating good inter-observer agreement. ORs show some kind of pattern - it appears that being a praporshnyk or officer in the army was protective. Non-response is low in all groups.	
		yes, as a sergeant	c(2,1)	1.16	0.50, 2.71	0.83	0.36, 1.89		20	16	20	56		
		yes, as a praporshnyk	c(3,1)	0.31	0.03, 3.30	0.41	0.03, 5.01		6	3	2	6		
		yes, as an officer	c(4,1)	0.47	0.04, 5.59	0.28	0.03, 2.97		6	2	3	6		
		no	c(5,1)	0.98	0.43, 2.23	0.97	0.42, 2.27		56	19	17	56		
F15	if yes, did he ever serve in a zone of conflict	97, 98 (don't know/refuse to ans)							2	2	0	4	(0.96%)	Kappa is high indicating good inter-observer agreement. ORs are close to 1, indicating limited predictive value of this question. Non-response is low in all groups.
		99 (system generated skip)							0	0	0	0	(0.00%)	
		yes	1	1.00 (ref)	.	1.00 (ref)	.	0.79	2	3	2	7		
		no	c(2,1)	1.47	0.23, 9.25	1.00	0.13, 7.43		163	55	54	163		
		97, 98 (don't know/refuse to ans)							1	0	0	1	(0.58%)	
F16	had he ever been in any kind of prison	99 (system generated skip)							16	11	10	37	(17.79%)	Kappa is 1 indicating extremely good inter-observer agreement. Response rate is very low for this question in all categories except 'no' making it difficult to calculate any ORs. However, there is some heterogeneity apparent between cases and controls. Non-response is 0.
		yes, during past year	1	1.00 (ref)	.	1.00 (ref)	.	1.00	1	0	0	1		
		yes, between 1-5 years ago	c(2,1)	.	.	.	.		2	0	0	2		
		yes, more than 5 years ago	c(3,1)	0.00	.	0.00	.		13	3	3	13		
		no	c(4,1)	0.00	.	0.00	.		192	66	63	192		
F17	how long ago was he registered disabled	97, 98 (don't know/refuse to ans)							0	0	0	0	(0.00%)	Kappa is high indicating good inter-observer agreement. Again, response rate is very low for this question in all categories making it difficult to calculate any ORs. Non-response is 0.
		99 (system generated skip)							0	0	0	0	(0.00%)	
		within last 6 months	2	1.00 (ref)	.	1.00 (ref)	.	0.86	1	0	0	1		
		6-12 months ago	c(3,2)	.	.	.	.		3	0	0	3		
		1-5 years ago	c(4,2)	0.00	.	0.00	.		18	4	4	18		
F17	how long ago was he registered disabled	5-10 years ago	c(5,2)	0.00	.	0.00	.		11	3	4	11	Kappa is high indicating good inter-observer agreement. Again, response rate is very low for this question in all categories making it difficult to calculate any ORs. Non-response is 0.	
		over 10 years ago but not whole life	c(6,2)	0.00	.	0.00	.		7	2	1	7		
		has always been disabled	c(7,2)	.	.	.	.		1	0	0	1		
		97, 98 (don't know/refuse to ans)							0	0	0	0		(0.00%)
		99 (system generated skip)							0	0	0	0		(0.00%)



Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
G1	did he experience. Serious illness of wife/partner	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2:1) c(3:1) c(4:1)	1.00 (ref)	.	1.00 (ref)	.	0.69	69	61	60	190	Kappa is high indicating good inter-observer agreement. Due to the low number of responses in categories other than baseline, it was not possible to calculate may ORs. Therefore it is difficult to determine from these data the predictive value of this question. Non-response is 0.
				1.77	0.31, 10.08	1.16	0.25, 5.42	4	2	3	9		
				0.00	.	0.00	.	0	2	1	3		
				0.00	.	0.00	.	0	4	2	6		
				0 (0.00%)		0 (0.00%)		0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		
G2	did he experience serious illness of other close family member/friend	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2:1) c(3:1) c(4:1)	1.00 (ref)	.	1.00 (ref)	.	0.63	55	48	48	151	Kappa is high indicating good inter-observer agreement. The ORs are slightly decreased in the higher strata indicating some predictive value. Non-response is low in all groups.
				0.98	0.35, 2.76	1.57	0.49, 5.05	9	8	5	22		
				0.50	0.14, 1.83	0.70	0.18, 2.77	4	7	5	16		
				0.58	0.15, 2.21	0.44	0.12, 1.56	4	6	8	18		
				1 (5.56%)		0 (0.00%)		0 (0.00%)	0 (0.00%)	0 (0.00%)	1 (1.75%)		
G3	did he experience death of wife/partner	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2:1) c(3:1) c(4:1)	1.00 (ref)	.	1.00 (ref)	.	1.00	71	68	64	203	The number of responses is very low, so no ORs have been calculated. Kappa is 1 indicating extremely good agreement using these data. It is difficult to determine the predictive value of this question with so few data.
				.	.	.	.	2	0	0	2		
				0.00	.	0.00	.	0	1	1	2		
				.	.	.	.	0	0	0	0		
				0 (0.00%)		0 (0.00%)		0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		
				0 (0.00%)		0 (0.00%)		0 (0.00%)	0 (0.00%)	1 (50.00%)	1 (20.00%)		
				0 (0.00%)		0 (0.00%)		0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
G4	did he experience death of other close family member/friend	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2.1) c(3.1) c(4.1)	1.00 (ref)	.	1.00 (ref)	.	0.62	44	36	31	111	Kappa is quite high indicating good inter-observer agreement. There appears to be an association with time since the trauma based on the lower ORs in strata 2 and 3. Non-response is low in all groups.
				0.60	0.24, 1.48	0.52	0.21, 1.29	11	15	15	41		
				0.30	0.08, 1.05	0.23	0.07, 0.84	4	11	12	27		
				1.91	0.66, 5.54	1.23	0.46, 3.31	14	6	8	28		
				0		0		0	(0.00%)	1	(3.03%)	0	
G5	did he experience divorce/separation from wife/partner	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2.1) c(3.1) c(4.1)	1.00 (ref)	.	1.00 (ref)	.	1.00	68	64	61	193	Kappa is 1 indicating very good agreement. Again, the number of responses is low making it difficult to evaluate this question. Non-response is low in all groups.
				.		.		3	0	0	3		
				.		.		0	0	0	0		
				0.19	0.02, 1.71	0.18	0.02, 1.63	1	5	5	11		
				1		1		1	(1.37%)	0	(0.00%)	0	
G6	did he experience serious financial problems	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2.1) c(3.1) c(4.1)	1.00 (ref)	.	1.00 (ref)	.	0.50	54	49	37	140	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is slightly higher than the preceding questions. The low OR in the first stratum indicates that this category (recent financial problems) may have predictive value.
				0.45	0.14, 1.44	0.29	0.09, 0.91	5	10	12	27		
				1.21	0.26, 5.72	0.91	0.19, 4.36	4	3	3	10		
				1.21	0.39, 3.75	0.42	0.16, 1.14	8	6	13	27		
				2	(10.53%)	1	(5.00%)	1	(3.45%)	4	(5.88%)	0	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments	
				OR	95% CI	OR	95% CI		case proxy	control proxy	total		
G7	did he experience other serious problems involving family/friend	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2,1) c(3,1) c(4,1)	1.00 (ref)	-	1.00 (ref)	-	0.75	59	55	172	Kappa is high indicating good inter-observer agreement. There is no clear pattern apparent from the ORs, which are all non-significant. Non-response is quite high. This question may not be performing well.	
				2.46	0.45, 13.38	1.17	0.30, 4.59	5	2	4	11		
				2.95	0.29, 29.73	0.93	0.18, 4.85	3	1	3	7		
				0.49	0.09, 2.82	0.62	0.10, 3.90	2	4	3	9		
								4	(28.57%)	4	(36.36%)		1
		97, 98 (don't know/refuse to ans) 99 (system generated skip)						0	(0.00%)	0	(0.00%)	0	(0.00%)
G8	did he experience other serious work or employment-related problems	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2,1) c(3,1) c(4,1)	1.00 (ref)	-	1.00 (ref)	-	0.58	54	51	158	Kappa is moderate, indicating reasonable inter-observer agreement. Non-response is slightly higher among proxies than the control. No clear pattern is apparent from the ORs. This question may not be performing well.	
				1.31	0.42, 4.05	0.94	0.33, 2.72	8	6	8	22		
				0.98	0.27, 3.61	1.18	0.30, 4.67	5	5	4	14		
				1.64	0.37, 7.26	1.57	0.35, 6.99	5	3	3	11		
								1	(5.26%)	2	(12.50%)		0
		97, 98 (don't know/refuse to ans) 99 (system generated skip)						0	(0.00%)	0	(0.00%)	0	(0.00%)
G9	did he experience 'other'	no yes, in past 12 months yes, 1-2 years ago yes, 2-5 years ago	1 c(2,1) c(3,1) c(4,1)	1.00 (ref)	-	1.00 (ref)	-	0.61	62	56	176	Kappa is reasonably high, indicating good inter-observer agreement. Again, no clear pattern is discernible from the ORs and non-response is high in most groups. This question is vague, which may explain its poor performance.	
				1.40	0.22, 8.77	1.35	0.22, 8.48	3	2	2	7		
				1.87	0.33, 10.72	3.61	0.38, 34.05	4	2	1	7		
				0.94	0.18, 4.85	0.54	0.12, 2.40	3	3	5	11		
								1	(9.09%)	4	(36.36%)		2
		97, 98 (don't know/refuse to ans) 99 (system generated skip)						0	(0.00%)	0	(0.00%)	0	(0.00%)
G10	what were his relations with his family	good, warm normal, peaceful tense frequent quarrels and conflicts	1 c(2,1) c(3,1) c(4,1)	1.00 (ref)	-	1.00 (ref)	-	0.49	16	19	50	Kappa is moderate, indicating reasonable inter-observer agreement. Although the ORs are not significant, there appears to be a trend when looking at control data. This is not so clear with control proxy data. Non-response is low in all groups.	
				0.78	0.34, 1.81	1.12	0.50, 2.54	35	42	37	114		
				1.72	0.50, 5.95	2.61	0.72, 9.50	11	6	5	22		
				1.72	0.50, 5.95	3.27	0.82, 13.01	11	6	4	21		
								0	(0.00%)	0	(0.00%)		1
		97, 98 (don't know/refuse to ans) 99 (system generated skip)						0	(0.00%)	0	(0.00%)	0	(0.00%)

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
G11	did he confide in family members or friends about personal matters	yes no	1 c(2,1)	1.00 (ref) 4.65	. 1.39, 15.51	1.00 (ref) 10.50	. 2.19, 173.78	0.00	50	62	65	177	Although kappa is 0 (an artifact of the data), the ORs are very high for both control and control proxy data. Non-response is higher in proxies than for the control, which is not unexpected due to the nature of this question. This question appears to have good predictive value
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							8 (10.96%)	3 (4.35%)	0 (0.00%)	11 (5.29%)	
G12	how often did he have contact with people in which he confided	every day every week every month less than once a month	1 c(2,1) c(3,1) c(4,1)	1.00 (ref) 1.11 0.47 0.00	. 0.41, 2.98 0.11, 2.01	1.00 (ref) 0.87 1.22 0.00	. 0.34, 2.19 0.23, 6.45	0.58	37	41	45	123	Kappa is moderate, indicating reasonably good inter-observer agreement. There is no clear trend observable from these ORs. Non-response is low in all groups. The predictive value of this question is unclear.
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							0 (0.00%)	2 (3.23%)	0 (0.00%)	2 (1.13%)	
G13	had he been more withdrawn from household life during the past year compared with previously	yes, more no no, less	1 c(3,1) c(2,1)	1.00 (ref) 2.11 8.57	. 0.68, 1.84, 39.86	1.00 (ref) 1.93 9.17	. 0.61, 6.07 1.85, 43.41	0.29	5	12	11	28	Kappa is low, indicating poor inter-observer agreement. The ORs show a clear trend, but this may not be reliable enough when taking the low kappa into account. This question may be too difficult for proxies to answer.
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							23 (31.51%)	7 (10.14%)	1 (1.52%)	31 (14.90%)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
J1	any other doctor-diagnosed diseases?	yes	1	1.00 (ref)	1.00 (ref)	1.00 (ref)	0.64	38	34	27	99	Kappa is quite high, indicating quite good inter-observer agreement. The ORs are non-significant and not far from 1. This question has limited predictive value. Non-response is low in all groups.	
		no	c(2,1)	0.98 0.50-1.93	0.82 0.31-1.22	0.82 0.31-1.22	0	31	39	104			
J2	what are those diseases?	97, 98 (don't know/refuse to ans)						1	4	5	5	Kappa is high for all categories where it was possible to calculate it, except for the last category, 'other'. However, low agreement is expected here because of the vague nature of the question.	
		99 (system generated skip)					0	0	0	0	0		
		cancer	1			1.00	73	68	65	206			
		no					0	1	1	2			
		heart disease	2			1.00	67	66	63	196			
		no					6	3	3	12			
		hypertension	3			0.93	67	60	58	185			
		no					6	9	8	23			
		diabetes	4			-	72	69	66	207			
		no					1	0	0	1			
		tuberculosis	5			-	71	69	66	206			
no					2	0	0	2					
hepatitis	6			1.00	69	68	65	202					
no					4	1	1	6					
stroke	7			1.00	72	68	65	205					
no					1	1	1	3					
alcohol dependency	8			0.65	67	65	64	196					
no					6	4	2	12					
depression	9			0.79	70	66	64	200					
no					3	3	2	8					
other psychiatric conditions	10			-	69	69	66	204					
no					4	0	0	4					
other	11			0.56	48	44	45	137					
no					25	25	21	71					

Q	Question text	Comparison strata	strata codes	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
J3	How often hospitalized during the past year	yes, once	1	1.00 (ref)	1.00 (ref)	1.00 (ref)	.	0.91	19	7	9	35	Kappa is high, indicating very good inter-observer agreement. There is no apparent significant difference here between being hospitalized once or more than once, but never being hospitalized is protective. This question has predictive value. Non-response is 0.
		yes, more than once	c(2,1)	0.66	0.16, 2.74	0.85	0.22, 3.35		9	5	5	19	
		no	c(3,1)	0.29	0.11, 0.78	0.41	0.17, 1.01		45	57	52	154	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							0	0	0	0	
J7	When did he last visit the polyclinic	within the last few days	1	-	-	-	-	0.78	4	2	2	8	Kappa is high, indicating very good inter-observer agreement. Non-response is higher in proxies than for the control, indicating that this question may be difficult for proxies to answer.
		1 week ago	c(2,1)						2	5	4	11	
		2-4 weeks ago	c(3,1)						9	7	5	21	
		1-6 months ago	c(4,1)						20	19	22	61	
		7-12 months ago	c(5,1)						13	12	11	36	
		over 1 year ago	c(6,1)						18	15	21	54	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)						7	9	1	17	0	
								0	0	0	0	0	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments				
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total					
J8	was he registered disabled	no yes, disabled from birth yes, disabled from war yes, disabled due to disease yes, disabled due to occupational disease yes, due to Chernobyl involvement yes, due to an accident at work yes, due to other accidents 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1) c(3,1) c(4,1) c(5,1) c(6,1) c(7,1) c(8,1)					1.00	50	60	57	167	Kappa is 1 indicating excellent inter-observer agreement. Non-response is 0. There are no responses in any categories except 'no', 'disabled due to disease' and 'disabled due to an accident at work'. However, the other categories may be necessary at a later stage. Perhaps we should alter the categories for this question?				
									2	0	0	2					
									0	0	0	0					
									15	7	7	29					
									0	0	0	0					
									0	0	0	0					
									1	0	0	1					
									0	0	0	0					
									0	(0.00%)	0	(0.00%)		0	(0.00%)		
									0	(0.00%)	0	(0.00%)		0	(0.00%)		
J10	how tall was he	height between 155 and 196 cm 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1					0.84	66	64	66	196	Weighted kappa was calculated based on actual height given. Inter-observer agreement is very good. Non-response is higher for proxies than for the control indicating that this question is difficult for proxies.				
									7	(9.55%)	5	(7.25%)		0	(0.00%)	12	(5.77%)
									0	(0.00%)	0	(0.00%)		0	(0.00%)	0	(0.00%)
									5	5	5	10					
									4	6	6	10					
									2	1	1	3					
									4	1	1	5					
									2	1	1	3					
									0	1	1	1					
									56	(76.71%)	54	(78.26%)		110	(77.46%)		
									0	(0.00%)	0	(0.00%)	0	(0.00%)			
J11	is he taller or shorter than you	taller than me by 20 cm taller than me by 10 cm taller than me by 5 cm same height as me shorter than me by 5 cm shorter than me by 10cm 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1) c(3,1) c(4,1) c(5,1) c(6,1)					-	5	5	5	10	Kappa could not be calculated as the control is not asked this question. Non-response was high among both proxies indicating that this question is not performing well.				
									4	6	6	10					
									2	1	1	3					
									4	1	1	5					
									2	1	1	3					
									0	1	1	1					
									56	(76.71%)	54	(78.26%)		110	(77.46%)		
									0	(0.00%)	0	(0.00%)		0	(0.00%)		
									0	(0.00%)	0	(0.00%)		0	(0.00%)		
									0	(0.00%)	0	(0.00%)		0	(0.00%)		

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
K1	has he broken any bones during past year	yes	1	1.00(ref)	-	1.00(ref)	-	0.79	10	2	3	15	kappa is very high, indicating very good inter-observer agreement. The ORs are low showing that this question may have good predictive value, although they are non-significant. Non-response is zero.
		no	c(1,0)	0.19	0.04, 0.92	0.30	0.08, 1.17		63	67	63	193	
K2	does he cough when he gets up in the morning	97, 98 (don't know/refuse to ans)							0	0	0	0	Kappa is high, showing good inter-observer agreement. OR are quite low and all very similar and mainly significant, suggesting a binary association. Non-response is very low in all groups.
		99 (system generated skip)							0	0	0	0	
		always	1	1.00(ref)	-	1.00(ref)	-	0.61	32	15	12	59	
		sometimes	c(2,1)	0.38	0.15, 0.95	0.33	0.12, 0.89		16	20	18	54	
		rarely	c(3,1)	0.30	0.09, 0.97	0.44	0.12, 1.62		7	11	6	24	
never	c(4,1)	0.33	0.13, 0.82	0.20	0.08, 0.53		16	23	30	69			
K3	can he climb a flight of stairs without becoming breathless	97, 98 (don't know/refuse to ans)							2	0	0	2	Kappa is high, indicating good inter-observer agreement. OR display a trend, as they increase sharply and are all significant, suggesting that this question has predictive value. Non-response is low in all categories, although higher in those than in the control group, suggesting this question is slightly difficult for proxies to answer.
		99 (system generated skip)							0	0	0	0	
		yes, easily	1	1.00(ref)	-	1.00(ref)	-	0.70	42	59	58	159	
		yes, with some difficulty	c(2,1)	3.61	1.34, 9.74	4.14	1.46, 11.79		18	7	6	31	
		no, too difficult	c(3,1)	12.64	1.40, 114.09	6.21	1.21, 31.95		9	1	2	12	
K4	how difficult is it for him to walk about 1km	97, 98 (don't know/refuse to ans)							4	2	0	6	As per K3. Additionally, ORs are clearly higher using control data compared with control proxy data. This indicates that proxies may tend to underestimate the ability of the subject.
		99 (system generated skip)							0	0	0	0	
		not at all difficult	1	1.00(ref)	-	1.00(ref)	-	0.65	36	56	58	150	
		slightly difficult	c(2,1)	3.58	1.47, 8.70	6.18	2.14, 17.84		23	10	6	39	
		very difficult/impossible	c(3,1)	6.22	1.54, 25.16	9.67	1.86, 50.22		12	3	2	17	
97, 98 (don't know/refuse to ans)								2	0	0	2		
99 (system generated skip)								0	0	0	0		



Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
K5	did he appear to have lost a significant amount of weight during the past year	yes	1	1.00(ref)	.	1.00(ref)	.	0.66	31	10	8	49	Kappa is high, indicating good inter-observer agreement. OR are low and significant, suggesting that this question has predictive value. Non-response is low in all categories.
		no	c(1,0)	0.22	0.09, 0.55	0.18	0.07, 0.46		41	59	58	158	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							1 (1.37%)	0 (0.00%)	0 (0.00%)	1 (0.48%)	
K6	during the past months, has he been able to carry out daily activities	no, not for a long time	1	1.00(ref)	.	1.00(ref)	.	0.00	2	1	0	3	There is very little heterogeneity in the responses to this question, therefore it was not possible to calculate ORs or kappa using these data. The numbers are too small to draw any firm conclusions, although this question does not appear to be worrying and should possibly be dropped.
		no, not for 6 months	c(2,1)	.	.	.	.		3	0	0	3	
		no, not for 1 month	c(3,1)	.	.	.	.		7	0	0	7	
		yes, up to now (death)	c(4,1)	0.45	0.04, 5.14	0.00	.		61	68	66	195	
K7	does he do physical exercise in his leisure time	97, 98 (don't know/refuse to ans) 99 (system generated skip)							0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	Kappa is high indicating good inter-observer agreement. ORs show a trend, although they are not significant. This question appears to have predictive value. Non-response is zero.
		yes, several times a week +	1	1.00(ref)	.	1.00(ref)	.	0.63	5	11	12	28	
		yes, sometimes	c(2,1)	1.60	0.38, 6.65	1.28	0.33, 5.04		8	11	15	34	
K9	does he have a generally active lifestyle	never	c(3,1)	2.81	0.89, 8.82	3.69	1.17, 11.69		60	47	39	146	Kappa is low, indicating poor inter-observer agreement. However, a trend is apparent. OR are higher when using control data, indicating that proxies tend to under-report activity levels of the subject. This question may be hard to answer due to the vagueness of the wording and should possibly be modified to be more objective.
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	
		yes, very active	1	1.00(ref)	.	1.00(ref)	.	0.31	6	13	21	40	
K9	does he have a generally active lifestyle	yes, moderately active	c(2,1)	1.84	0.63, 5.36	3.33	1.18, 9.41		40	47	42	129	Kappa is low, indicating poor inter-observer agreement. However, a trend is apparent. OR are higher when using control data, indicating that proxies tend to under-report activity levels of the subject. This question may be hard to answer due to the vagueness of the wording and should possibly be modified to be more objective.
		no, not particularly active	c(3,1)	6.26	1.60, 24.47	30.33	3.84, 239.73		26	9	3	38	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							1 (1.37%)	0 (0.00%)	0 (0.00%)	1 (0.48%)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments				
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total					
L1	how often did he drink beer	never or almost never	7	1.00(ref)	.	1.00(ref)	.	0.77	29	16	14	59	Kappa is high, indicating good inter-observer agreement. Drinking beer may be protective, although there is no clear evidence of a dose-response from these data. The ORs are mainly non-significant. Non-response is low in all groups.				
		a few times per year	c(6,7)	0.83	0.20, 3.42	0.48	0.13, 1.82		6	4	6	16					
		1-3 times a month	c(5,7)	0.28	0.09, 0.87	0.34	0.10, 1.13		7	14	10	31					
		once or twice a week	c(4,7)	0.48	0.18, 1.28	0.35	0.13, 0.94		13	15	18	46					
		three or four times a week	c(3,7)	0.62	0.20, 1.95	0.43	0.14, 1.35		9	8	10	27					
		nearly every day	c(2,7)	0.32	0.08, 1.31	0.48	0.10, 2.28		4	7	4	15					
		every day or more often	c(1,7)	0.55	0.10, 3.14	0.36	0.07, 1.92		3	3	4	10					
		97, 98 (don't know/refuse to ans)							2	(2.7%)	2	(2.9%)		0	(0.0%)	4	(1.9%)
		99 (system generated skip)							0	(0.0%)	0	(0.0%)		0	(0.0%)	0	(0.0%)
		L2	how often did he drink wine	never or almost never	7	1.00(ref)	.	1.00(ref)	.	0.61	44	39		36	119	Kappa is quite high, indicating good inter-observer agreement. Drinking wine 'nearly every day' appears to have some predictive value, although the ORs are not significant. Due to the low numbers of responses in the 'every day' category, it was not possible to calculate ORs using these data for that stratum. Non-response is very low in all groups.	
				a few times per year	c(6,7)	0.82	0.34, 1.97	0.76	0.32, 1.83		13	14		14	41		
1-3 times a month	c(5,7)			0.55	0.17, 1.86	0.41	0.13, 1.33		5	8	10	23					
once or twice a week	c(4,7)			0.59	0.09, 3.77	0.55	0.09, 3.30		2	3	3	8					
three or four times a week	c(3,7)			0.89	0.17, 4.69	1.23	0.19, 7.84		3	3	2	8					
nearly every day	c(2,7)			2.66	0.26, 27.25	2.45	0.24, 25.18		3	1	1	5					
every day or more often	c(1,7)			.	.	.	.		1	0	0	1					
97, 98 (don't know/refuse to ans)									2	(2.7%)	1	(1.4%)	0	(0.0%)	3		(1.4%)
99 (system generated skip)									0	(0.0%)	0	(0.0%)	0	(0.0%)	0		(0.0%)

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments							
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total								
13	how often did he drink spirits	never or almost never a few times per year 1-3 times a month once or twice a week three or four times a week nearly every day every day or more often	7	1.00(ref)	-	1.00(ref)	-	0.76	12	16	15	43	Kappa is high, indicating good inter-observer agreement. There appears to be a binary association between frequency of drinking spirits and case/control status; the three strata corresponding to most frequent drinking of spirits have very high ORs, while the three lower strata have very moderate ORs. The ORs show good concordance, although are mainly non-significant. The question appears to have reasonable predictive value. Non-response is very low in all groups.							
				c(6,7)	1.02	0.36, 2.91	1.25	0.42, 3.75	13	17	13	43								
				c(5,7)	0.48	0.16, 1.50	0.45	0.15, 1.42	8	22	22	52								
				c(4,7)	2.10	0.61, 7.25	1.38	0.43, 4.39	11	7	10	28								
				c(3,7)	12.00	1.03, 139.16	5.63	0.89, 35.55	9	1	2	12								
				c(2,7)	4.89	1.00, 24.01	6.88	1.08, 43.62	11	3	2	16								
				c(1,7)	6.00	0.95, 37.98	5.63	0.89, 35.55	9	2	2	13								
				97, 98 (don't know/refuse to ans)	-	-	-	-	0	0	0	0		1	0	1	(0.58)			
				99 (system generated skip)	-	-	-	-	0	0	0	0		0	0	0	0	0	0	(0.08)
				14	on which days did he drink beer	every day only at the weekend only on weekdays any day only on holidays/celebrations never or almost never	4	1.00(ref)	-	1.00(ref)	-	0.69		5	3	3	11	Kappa is high indicating good inter-observer agreement. The majority of responses were 'any day' which may have driven the high kappa value. ORs are similar for controls and control proxies, but none is significant. Non-response is higher in control proxies than controls.		
c(1,4)	0.21	0.03, 1.44	0.23					0.03, 1.55	5	14	13	32								
c(2,4)	0.00	-	0.00					-	0	1	1	2								
c(3,4)	0.58	0.12, 2.70	0.56					0.12, 2.61	28	29	30	87								
c(5,4)	1.20	0.12, 12.04	0.80					0.09, 6.85	4	2	3	9								
c(6,4)	1.80	0.31, 10.29	1.80					0.31, 10.29	18	6	6	30								
97, 98 (don't know/refuse to ans)	-	-	-					-	3	3	0	0	0	6	(3.48)					
99 (system generated skip)	-	-	-					-	10	11	10	10	10	10	31	(14.98)				
15	on which days did he drink wine	every day only at the weekend only on weekdays any day only on holidays/celebrations never or almost never	4					1.00(ref)	-	1.00(ref)	-	0.69	3	0	0	3	Kappa is high, indicating good inter-observer agreement. Using PG4 data, the number of responses in category 'every day' which was used as baseline was too low to permit OR calculations. Examining the number of responses in each category is not sufficient to ascertain the predictive value of the question. Non-response is higher in control proxies than controls.			
								c(1,4)	0.00	-	0.00	-	2	5	6	13				
				c(2,4)	0.00	-	0.00	-	0	1	2	3								
				c(3,4)	0.00	-	0.00	-	12	8	7	27								
				c(5,4)	0.00	-	0.00	-	10	12	14	36								
				c(6,4)	0.00	-	0.00	-	33	29	27	89								
				97, 98 (don't know/refuse to ans)	-	-	-	-	3	3	0	0	0	6	(3.48)					
				99 (system generated skip)	-	-	-	-	10	11	10	10	10	31	(14.98)					

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments	
				OR	95% CI	OR	95% CI		case proxy	control proxy	control total		
16	on which days did he drink spirits	every day	4	1.00(ref)	.	1.00(ref)	.	0.62	10	1	12	Kappa is quite high, indicating good inter-observer agreement. There is suggestion of a binary trend, whereby drinking spirits every day is predictive by comparison with every other strata. The ORs show good concordance and are extremely low for most strata, although some are not significant. The lack of significance may be explained by the low number of responses. This question appears to be reasonably reliable with good predictive value. Non-response is low in all groups.	
				c(1,4)	0.09	0.01, 1.22	0.06	0.00, 0.93	7	8	11		26
				c(2,4)	0.00	.	0.00	.	0	1	1		2
				c(3,4)	0.17	0.02, 1.58	0.22	0.02, 1.99	33	19	15		67
				c(5,4)	0.04	0.00, 0.59	0.05	0.00, 0.61	10	23	22		55
				c(6,4)	0.04	0.00, 1.38	0.03	0.00, 1.25	2	5	6		13
17	how much beer was usually drunk on one occasion	none	5	1.00(ref)	.	1.00(ref)	.	0.36	18	4	26	Kappa is low, indicating poor inter-observer agreement. Although kappa is low, there is reasonable concordance between ORs among the lower strata. For the higher strata, the numbers are very low which explains the discordance in ORs. The ORs are very low for all strata. This question appears to have good predictive power. Non-response is higher in control probes than controls.	
				c(1,5)	0.19	0.05, 0.70	0.18	0.05, 0.67	22	26	27		75
				c(2,5)	0.13	0.03, 0.55	0.11	0.03, 0.48	12	21	24		57
				c(3,5)	0.11	0.01, 2.00	0.22	0.01, 5.00	1	2	1		4
				c(4,5)	.	.	.	.	1	0	0		1
				c(5,5)	.	.	.	.	9	14	5		14
18	how much wine was usually drunk on one occasion	none	6	1.00(ref)	.	1.00(ref)	.	0.58	10	10	31	No clear trend is observable. ORs do not appear to be particularly concordant despite kappa being quite reasonable. ORs are not particularly extreme, the previous value of LB is questionable. Non-response is higher in control probes than controls.	
				c(1,6)	0.98	0.33, 2.92	0.76	0.27, 2.16	9	8	10		27
				c(2,6)	0.56	0.19, 1.66	0.66	0.21, 2.02	7	11	9		27
				c(3,6)	1.05	0.29, 3.95	0.63	0.19, 2.08	6	5	8		19
				c(4,6)	1.17	0.24, 5.74	1.69	0.28, 10.12	4	3	2		9
				c(5,6)	.	.	.	.	1	0	0		1
		97, 98 (don't know/refuse to ans)		4	6.31	3	5.28	0	0	0	7	4.05	
				10	13.78	11	15.98	10	15.28	31	14.98		

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted happen	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
I.9	how much alcohol was usually drunk on one occasion	none	7	1.00(ref)	-	1.00(ref)	-	0.57	2	5	4	11	Kappa is reasonable indicating good inter-observer agreement. Again, it is rather difficult to identify any clear trend, although there is some suggestion of predictive value of the higher strata compared to baseline. Perhaps there are too many categories?
		between 50 - 100g	c(1,7)	2.50	0.26, 24.28	2.67	0.24, 30.15		4	4	3	11	
		between 100 - 200g	c(2,7)	1.43	0.22, 9.49	1.23	0.18, 8.65		8	14	13	35	
		between 200 - 300g	c(3,7)	3.25	0.48, 22.20	1.53	0.23, 9.98		13	10	17	40	
		between 300 - 400g	c(4,7)	1.88	0.25, 14.13	1.20	0.16, 9.08		6	8	10	24	
		between 400 - 500g	c(5,7)	3.75	0.52, 27.17	8.00	0.71, 90.45		12	8	3	23	
		more than 500g	c(6,7)	6.00	0.70, 51.69	4.00	0.49, 32.46		12	5	6	23	
I.10	what was the maximum quantity of beer drunk on one occasion	97, 98 (don't know/refuse to ans)							6 (9.58)	4 (6.94)	0 (0.08)	10 (5.68)	Kappa is reasonable indicating good inter-observer agreement. ORs are generally very low and significant and display similar patterns for controls and control proxies. It appears that drinking beer is protective. Blips have removed non-drivers from these data. It looks as though those alcohol drinkers who choose beer may not be drinking spirits, hence the protective effect. Non-response is much higher among control proxies than controls.
		99 (system generated skip)							10 (13.78)	11 (15.94)	10 (15.24)	31 (14.94)	
		none	5	1.00(ref)	-	1.00(ref)	-	0.59	18	3	3	24	
		1 bottle or less	c(1,5)	0.13	0.03, 0.67	0.20	0.04, 1.03		11	14	9	34	
		2-4 bottles	c(2,5)	0.13	0.03, 0.62	0.09	0.02, 0.44		14	18	26	58	
		5-6 bottles	c(3,5)	0.25	0.03, 2.46	0.07	0.01, 0.67		3	2	7	12	
		more than 6 bottles	c(4,5)	0.08	0.01, 0.65	0.07	0.01, 0.54		4	8	10	22	
I.11	what was the maximum quantity of wine drunk on one occasion	97, 98 (don't know/refuse to ans)							13 (20.68)	13 (22.41)	1 (1.68)	27 (15.38)	Kappa is reasonable indicating good inter-observer agreement. A trend is observable for the control ORs, but hard to detect for the control proxy data. ORs are not significant, again possibly explainable by the low numbers. Non-response is much higher among control proxies than controls.
		99 (system generated skip)							10 (13.78)	11 (15.94)	10 (15.28)	31 (14.94)	
		none	6	1.00(ref)	-	1.00(ref)	-	0.57	32	30	26	88	
		up to 200g	c(1,6)	1.13	0.31, 4.11	2.44	0.44, 13.47		6	5	2	13	
		between 200 - 400g	c(2,6)	1.88	0.50, 6.99	0.72	0.24, 2.16		8	4	9	21	
		between 400 - 600g	c(3,6)	0.75	0.18, 3.10	0.46	0.12, 1.80		4	5	7	16	
		between 600 - 1000g	c(4,6)	1.41	0.22, 9.15	0.41	0.09, 1.83		3	2	6	11	
more than 1 litre	c(5,6)	0.70	0.14, 3.45	0.41	0.09, 1.83		3	4	6	13			
I.11		97, 98 (don't know/refuse to ans)							7 (11.18)	8 (13.88)	0 (0.04)	15 (8.58)	
		99 (system generated skip)							10 (13.78)	11 (15.94)	10 (15.24)	31 (14.94)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments					
				OR	95% CI	OR	95% CI		case proxy	control proxy	control		total				
L12	what was the maximum quantity of spirits drunk on one occasion	none	7	1.00(ref)	-	1.00(ref)	-	0.54	2	4	4	10	Kappa is reasonable indicating good inter-observer agreement. No clear trend is observable. The ORs are high for the highest stratum, although they are discordant between controls and control proxies and not significant. The possible predictive value of this stratum should be interpreted with caution. Non-response is much higher among control proxies than controls.				
		between 50 - 100g	c(1,7)	3.00	0.20, 43.92	3.00	0.20, 43.92		3	2	2	7					
		between 100 - 200g	c(2,7)	1.67	0.19, 14.31	3.33	0.30, 36.99		5	6	3	14					
		between 200 - 300g	c(3,7)	2.00	0.26, 15.21	2.00	0.26, 15.21		8	8	8	24					
		between 300 - 400g	c(4,7)	1.00	0.10, 9.66	0.86	0.09, 8.07		3	6	7	16					
		between 400 - 500g	c(5,7)	1.73	0.26, 11.48	1.44	0.22, 9.39		13	15	18	46					
		more than 500g	c(6,7)	4.22	0.59, 30.44	2.71	0.41, 17.89		19	9	14	42					
L13	did he ever drink beer, spirits and/or wine on the same occasion	97, 98 (don't know/refuse to ans)							10	8	(13.8%)	0	(0.0%)	18	(10.2%)	Kappa is reasonable, indicating good inter-observer agreement. When taking the low number of responses in some strata for control/control proxies, the ORs can be considered to be concordant, as well as being very low and mostly significant. There is suggestion of a trend. This question has good predictive power. Non-response is higher among control proxies than controls.	
		99 (system generated)							10	(13.7%)	11	(15.9%)	10	(15.2%)	31		(14.9%)
		yes, often	1	1.00(ref)	-	1.00(ref)	-	0.59	12	3	1	1	16				
		yes, sometimes	c(2,1)	0.25	0.06, 1.05	0.08	0.01, 0.78		25	25	26	76					
		no, never	c(3,1)	0.19	0.04, 0.84	0.05	0.01, 0.58		19	25	29	73					
L14	did he ever drink large quantities of spirits without food	97, 98 (don't know/refuse to ans)							10	(13.7%)	11	(15.9%)	10	(15.2%)	31	(14.9%)	Kappa is reasonable indicating good inter-observer agreement. The ORs are reasonably concordant, and suggest for the first stratum a trend of a trend. This question appears to have good predictive value. Non-response is higher among control proxies than controls.
		99 (system generated)							15	3	2	20					
		always	1	1.00(ref)	-	1.00(ref)	-	0.58	18	8	4	30					
		sometimes	c(2,1)	0.45	0.10, 2.08	0.60	0.09, 3.86		26	42	50	118					
		never	c(3,1)	0.12	0.03, 0.52	0.07	0.01, 0.39		4	(6.3%)	5	(8.6%)	0	(0.0%)	9	(5.1%)	
		97, 98 (don't know/refuse to ans)							10	(13.7%)	11	(15.9%)	10	(15.2%)	31	(14.9%)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	total	
L15	did he ever drink other substances	regularly	1	1.00(ref)	1.00(ref)	0.59		18	3	2	23	As per L13.
		sometimes	c(2,1)	0.51	0.10, 2.94	0.24	0.04, 1.52	13	4	6	23	
L16	how often did he become excessively drunk	rarely/never	c(3,1)	0.10	0.02, 0.40	0.07	0.01, 0.37	29	50	48	127	As per L13.
		97, 98 (don't know/refuse to ans)						3	4 (4.8%)	1 (1.7%)	0 (0.0%)	
L17	did he ever drink alcohol before noon	99 (system generated skip)						10	11	10	31 (14.9%)	Kappa is reasonable indicating good inter-observer agreement. There is some suggestion that reporting of infrequently becoming excessively drunk may be predictive. The ORs are significant and clearly decline in the higher strata. The question appears to have good predictive value. Non-response is low in all groups.
		several times a week	1	1.00(ref)	1.00(ref)	0.54		23	5	3	31	
L17	did he ever drink alcohol before noon	once a week	c(2,1)	0.72	0.14, 3.72	0.43	0.07, 2.65	10	3	3	16	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		several times a month	c(3,1)	0.22	0.04, 1.32	0.52	0.04, 6.70	4	4	1	9	
L17	did he ever drink alcohol before noon	once a month	c(4,1)	0.09	0.01, 0.53	0.10	0.01, 0.80	4	10	5	19	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		less than once a month	c(5,1)	0.18	0.04, 0.75	0.07	0.01, 0.40	9	11	17	37	
L17	did he ever drink alcohol before noon	never or almost never	c(6,1)	0.12	0.03, 0.45	0.07	0.01, 0.34	13	24	26	63	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		97, 98 (don't know/refuse to ans)						0	0 (0.0%)	1 (1.7%)	1 (1.8%)	
L17	did he ever drink alcohol before noon	99 (system generated skip)						10	11	10	31 (14.9%)	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		no	1	1.00(ref)	1.00(ref)	0.41		18	37	36	91	
L17	did he ever drink alcohol before noon	yes, occasionally	c(2,1)	3.60	1.49, 8.64	3.50	1.45, 8.44	28	16	16	60	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		yes, frequently	c(3,1)	8.74	2.22, 34.35	8.50	2.17, 31.37	17	4	4	25	
L17	did he ever drink alcohol before noon	97, 98 (don't know/refuse to ans)						0	0 (0.0%)	1 (1.7%)	1 (0.6%)	Kappa is at the lower end of the 'moderately' category, indicating limited inter-observer agreement. L17 shows evidence of a trend. Non-response is low in all groups.
		99 (system generated skip)						10	11	10	31 (14.9%)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments					
				OR	95% CI	OR	95% CI		case proxy	control proxy	total						
L18	how often did he have a hangover?	every day	1	1.00(w)	-	1.00(w)	-	0.56	3	2	22	As per L16					
		several times a week	c(2,1)	0.76	0.13, 4.55	1.53	0.12, 19.59		13	3	1		17				
		about once a week	c(3,1)	0.26	0.03, 2.61	0.12	0.01, 1.35		3	2	3		8				
		several times a month	c(4,1)	0.12	0.01, 1.35	0.24	0.01, 4.52		2	3	1		6				
		about once a month	c(5,1)	0.09	0.01, 0.57	0.07	0.01, 0.61		6	12	10		28				
		less than once a month	c(6,1)	0.18	0.03, 0.95	0.08	0.01, 0.56		9	9	14		32				
		never or almost never	c(7,1)	0.07	0.01, 0.39	0.05	0.01, 0.36		10	25	25		60				
		regular salaries							3	(4.8%)	1		(1.7%)	0	(0.0%)	4	(2.3%)
		99 (system generated skip)							10	(13.7%)	11		(15.9%)	10	(15.2%)	31	(14.9%)
		L19	how often did he fail to fulfill work obligation?	every day	1	1.00(w)	-	1.00(w)	-	0.56	7		2	10	Kappa is reasonable indicating good inter-observer agreement. Several of the middle strata showed low or no responses, indicating that the categories may need to be redefined. Again, the low numbers may explain lack of significance of ORs, but there is convincing suggestion of a trend. This question may have predictive value. Non-response is higher for case proxies than the other two groups.		
several times a week	c(2,1)			1.43	0.09, 22.58	-	-		5	1	0	6					
about once a week	c(3,1)			-	-	-	-		0	0	0	0					
several times a month	c(4,1)			-	-	-	-		3	0	0	3					
about once a month	c(5,1)			1.29	0.13, 12.26	1.29	0.06, 26.62		9	2	1	12					
less than once a month	c(6,1)			1.00	0.10, 9.84	0.33	0.02, 4.60		7	2	3	12					
never	c(7,1)			0.15	0.02, 0.84	0.08	0.01, 0.74		27	51	51	129					
97, 98 (don't know/refuse to ans)									5	(7.9%)	0	(0.0%)	0	(0.0%)		5	(2.8%)
99 (system generated skip)									10	(13.7%)	11	(15.9%)	10	(15.2%)		31	(14.9%)
L20	how often did he fail to fulfill personal obligation?			every day	1	1.00(w)	-	1.00(w)	-	0.52	13	2	1	16		Kappa is reasonable indicating good inter-observer agreement. There is some evidence of a trend, although this is not convincing from these data. Non-response is low in all groups.	
		several times a week	c(2,1)	1.15	0.14, 9.71	-	-		15	2	0	17					
		about once a week	c(3,1)	0.23	0.02, 2.80	0.12	0.01, 2.39		3	2	2	7					
		several times a month	c(4,1)	0.10	0.01, 1.53	-	-		2	3	0	5					
		about once a month	c(5,1)	0.10	0.01, 1.53	0.15	0.01, 4.66		2	3	1	6					
		less than once a month	c(6,1)	0.09	0.01, 0.88	0.06	0.00, 1.16		4	7	5	16					
		never	c(7,1)	0.09	0.01, 0.49	0.04	0.00, 0.38		21	38	46	105					
		97, 98 (don't know/refuse to ans)							3	(4.8%)	1	(1.7%)	1	(1.8%)	5		(2.8%)
		99 (system generated skip)							10	(13.7%)	11	(15.9%)	10	(15.2%)	31		(14.9%)



Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments				
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total					
L21	did he ever go to sleep with his clothes on	every day	1	1.00(ref)	-	1.00(ref)	-	0.48	10	1	1	12	Kappa is reasonable indicating reasonable inter-observer agreement. Low numbers in some categories may explain non-significance of the ORs, but there is clear evidence of a trend. The question appears to have good predictive value. Non-response is low in all groups.				
		several times a week	c(2,1)	1.00	0.05, 19.60	-	-	-	10	1	0	11					
		about once a week	c(3,1)	0.40	0.02, 9.24	-	-	-	4	1	0	5					
		several times a month	c(4,1)	0.25	0.02, 4.10	0.50	0.02, 10.92	-	5	2	1	8					
		about once a month	c(5,1)	0.03	0.00, 0.93	0.10	0.00, 2.06	-	3	9	3	15					
		less than once a month	c(6,1)	0.12	0.01, 1.57	0.06	0.00, 0.93	-	7	6	11	24					
		never	c(7,1)	0.06	0.01, 0.63	0.06	0.01, 0.60	-	23	37	39	99					
		97, 98 (don't know/refuse to ans)							1	(1.6%)	1	(1.7%)		3	(1.7%)		
		99 (system generated skip)							10	(13.7%)	11	(15.9%)		10	(15.2%)	31	(14.9%)
		L22	did he ever drink alone	yes, often	1	1.00(ref)	-	1.00(ref)	-	0.62	23	9		6	38	Kappa is quite high, indicating good inter-observer agreement. A clear trend is observable. The question has good predictive value. Non-response is low in all groups.	
yes, sometimes	c(2,1)			0.47	0.17, 1.29	0.29	0.09, 0.88	-	23	19	21	63					
no, never	c(3,1)			0.22	0.07, 0.62	0.14	0.04, 0.48	-	16	29	29	74					
97, 98 (don't know/refuse to ans)									1	(1.6%)	1	(1.7%)	0	(0.0%)	2		(1.1%)
99 (system generated skip)									10	(13.7%)	11	(15.9%)	10	(15.2%)	31		(14.9%)
at home	1			1.00(ref)	-	1.00(ref)	-	0.84	56	49	51	156					
	c(1,0)			1.34	0.63, 2.86	0.97	0.44, 2.14	-	17	20	15	52					
97, 98 (don't know/refuse to ans)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
99 (system generated skip)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
L23_2	in bars or cafes			at home	1	1.00(ref)	-	1.00(ref)	-	0.17	13	12	22	47	Kappa for this question is very high, indicating very good inter-observer agreement. This is as expected, since this is easily observable behaviour. The ORs are not all extreme, indicating that although reliable, this question has low predictive value. Non-response is zero for all groups.		
			c(1,0)	1.03	0.43, 2.45	0.43	0.19, 0.97	-	60	57	44	161					
		97, 98 (don't know/refuse to ans)							0	(0.0%)	0	(0.0%)	0	(0.0%)			
		99 (system generated skip)							0	(0.0%)	0	(0.0%)	0	(0.0%)			
		in bars or cafes	1	1.00(ref)	-	1.00(ref)	-	0.32	23	9	10	42					
			c(1,0)	3.07	1.27, 7.41	2.58	1.10, 6.05	-	50	60	56	166					
		97, 98 (don't know/refuse to ans)							0	(0.0%)	0	(0.0%)	0	(0.0%)			
		99 (system generated skip)							0	(0.0%)	0	(0.0%)	0	(0.0%)			
		in streets and parks	1	1.00(ref)	-	1.00(ref)	-	0.32	23	9	10	42					
		L23_3	in streets and parks	at home	1	1.00(ref)	-	1.00(ref)	-	0.32	23	9	10	42		Kappa for this question is low, indicating poor inter-observer agreement. ORs are substantially higher than in other L23 options, and although desirably, are significant. This question may have some predictive value. Non-response is zero for all groups.	
	c(1,0)			3.07	1.27, 7.41	2.58	1.10, 6.05	-	50	60	56	166					
97, 98 (don't know/refuse to ans)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
99 (system generated skip)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
in streets and parks	1			1.00(ref)	-	1.00(ref)	-	0.32	23	9	10	42					
	c(1,0)			3.07	1.27, 7.41	2.58	1.10, 6.05	-	50	60	56	166					
97, 98 (don't know/refuse to ans)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
99 (system generated skip)									0	(0.0%)	0	(0.0%)	0	(0.0%)			
in streets and parks	1			1.00(ref)	-	1.00(ref)	-	0.32	23	9	10	42					
	c(1,0)			3.07	1.27, 7.41	2.58	1.10, 6.05	-	50	60	56	166					

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments			
				OR	95% CI	OR	95% CI		same proxy	control proxy	control	total				
L23_4		in other public places	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	0.47	8	5	4	17	Kappa is moderate, indicating reasonable inter-observer agreement. The ORs are not significant and not extreme. Non-response is zero for all groups.			
				c(1,0)	1.58	0.49, 5.11	1.91	0.54, 6.72	65	64	62	191				
L23_5		97, 98 (don't know/refuse to ans) 99 (system generated skip) at friend's home	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	0.52	35	30	25	90	Kappa is low, indicating poor inter-observer agreement. ORs are similar and quite low, but the number of responses is low and the ORs are non-significant. Non-response is zero for all groups.			
				c(1,0)	1.20	0.42, 2.33	1.51	0.76, 2.99	38	39	41	118				
L23_6		other place (specify) 97, 98 (don't know/refuse to ans) 99 (system generated skip)	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	0.23	7	14	14	35	Kappa is very high for these three questions, indicating very good inter-observer agreement. This demonstrates that binge-drinking is something that is easily observable. Whilst some ORs are not significant, this can be explained by the low numbers of responses for some categories. However, the magnitude of the ORs is extremely low indicating that these questions have very high predictive value. Non-response is zero for all groups, but this is expected since many respondents are filtered away from answering these questions.			
				c(1,0)	0.42	0.15, 1.12	0.39	0.15, 1.06	66	55	52	173				
L24	did he have one or more binges in the year before death	yes, often	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	0.93	25	2	1	28	Kappa is very high for these three questions, indicating very good inter-observer agreement. This demonstrates that binge-drinking is something that is easily observable. Whilst some ORs are not significant, this can be explained by the low numbers of responses for some categories. However, the magnitude of the ORs is extremely low indicating that these questions have very high predictive value. Non-response is zero for all groups, but this is expected since many respondents are filtered away from answering these questions.			
				c(2,1)	0.27	0.04, 1.67	0.14	0.01, 1.43	17	5	5	27				
L25	did he have one or more binges in the week before death	no, never	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	0.67	34	3	2	39	Kappa is very high for these three questions, indicating very good inter-observer agreement. This demonstrates that binge-drinking is something that is easily observable. Whilst some ORs are not significant, this can be explained by the low numbers of responses for some categories. However, the magnitude of the ORs is extremely low indicating that these questions have very high predictive value. Non-response is zero for all groups, but this is expected since many respondents are filtered away from answering these questions.			
				c(2,1)	0.03	0.01, 0.24	0.02	0.00, 0.22	21	51	50	122				
L26	did he have one or more binges in the week before death	yes	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	1.00	29	2	1	32	Kappa is very high for these three questions, indicating very good inter-observer agreement. This demonstrates that binge-drinking is something that is easily observable. Whilst some ORs are not significant, this can be explained by the low numbers of responses for some categories. However, the magnitude of the ORs is extremely low indicating that these questions have very high predictive value. Non-response is zero for all groups, but this is expected since many respondents are filtered away from answering these questions.			
				c(2,1)	0.15	0.02, 0.96	0.10	0.01, 0.81	7	4	4	15				
L26	did he have one or more binges in the week before death	no	1	1.00(ref)	1.00(ref)	1.00(ref)	1.00(ref)	1.00	6	1	1	8	Kappa is very high for these three questions, indicating very good inter-observer agreement. This demonstrates that binge-drinking is something that is easily observable. Whilst some ORs are not significant, this can be explained by the low numbers of responses for some categories. However, the magnitude of the ORs is extremely low indicating that these questions have very high predictive value. Non-response is zero for all groups, but this is expected since many respondents are filtered away from answering these questions.			
				c(2,1)	0.41	0.03, 5.61	0.21	0.01, 4.17	0	0	0	0				
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							38	(52.15)	68	(95.88)	64	(97.04)	170	(81.04)

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted binary	n				Comments				
				CR	95% CI	OR	95% CI		case proxy	control proxy	control	total					
L27	what was the quantity of beer drunk in the most recent binge	none	5	1.00(ref)	.	1.00(ref)	.	-	16	0	0	16	These questions are filtered, and the number of responses was extremely low for most categories in PSA. It is impossible to evaluate these questions based on the data available				
		1 bottle or less	c(1,5)	.	.	.	.		0	0	0	0					
		2-4 bottles	c(2,5)	0.00	.	0.00	.		2	1	1	4					
		5-6 bottles	c(3,5)	.	.	.	.		2	0	0	2					
		more than 6 bottles	c(4,5)	.	.	.	.		0	0	0	0					
		drank beer, but not sure of the quantity	c(6,5)	.	.	.	.		0	0	0	0					
		97, 98 (don't know/refuse to answer)							9	(31.0%)	1	(50.0%)		0	(0.0%)	10	(31.3%)
		99 (system generated skip)							44	(60.3%)	67	(97.1%)		65	(96.5%)	176	(84.6%)
		L28	what was the quantity of wine drunk in the most recent binge	none	6	1.00(ref)	.	1.00(ref)	.	-	16	1		0	17	These questions are filtered, and the number of responses was extremely low for most categories in PSA. It is impossible to evaluate these questions based on the data available	
				up to 200g	c(1,6)	.	.	.	.		1	0		0	1		
between 200 - 400g	c(2,6)			.	.	.	.		1	0	0	1					
between 400 - 600g	c(3,6)			.	.	.	.		0	0	0	0					
between 600 - 1000g	c(4,6)			0.06	0.00, 3.17	0.00	.		1	1	1	3					
more than 1 liter	c(5,6)			.	.	.	.		1	0	0	1					
drank wine, but not sure of the quantity	c(7,6)			.	.	.	.		3	0	0	3					
97, 98 (don't know/refuse to answer)									6	(20.7%)	0	(0.0%)	0	(0.0%)	6		(18.8%)
99 (system generated skip)									44	(60.3%)	67	(97.1%)	65	(96.5%)	176		(84.6%)

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments	
				OR	95% CI	OR	95% CI		case proxy	control proxy	total		
129	what was the median quantity of spirits drunk in the most recent binge	none	1	1.00(Inf)	1.00(Inf)	-	-	-	4	0	0	4	These questions are filtered, and the number of responses was extremely low for most categories in PS4. It is impossible to evaluate these questions based on the data available.
		between 50 - 100g	c(1,7)	.	.	.	.	.	0	0	0	0	
		between 100 - 200g	c(2,7)	.	.	.	.	.	0	0	0	0	
		between 200 - 300g	c(3,7)	.	.	.	.	.	1	0	0	1	
		between 300 - 600g	c(4,7)	.	.	.	.	.	0	0	0	0	
		between 400 - 500g	c(5,7)	.	.	.	.	.	4	0	0	4	
		more than 500g	c(6,7)	0.00	0.00	.	.	.	8	1	1	10	
130	during most recent binge did he drink any other alcoholic substances	yes	1	1.00(Inf)	1.00(Inf)	-	-	-	16	2	1	19	
		no	c(2,1)	.	.	.	.	.	9	0	0	9	
		97, 98 (don't know/refuse to ans)		4 (13.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (12.31)					
		99 (system generated skip)		44 (60.3%)	67 (97.1%)	75 (98.7%)	176 (84.6%)						
131	had he been arrested during past year	yes	1	1.00(Inf)	1.00(Inf)	0.63	.	.	18	7	5	30	Kappa is high, indicating good inter-observer agreement, and the ORs are low and significant. This question appears to have good predictive value. Non-response is low in all groups.
		no	c(2,1)	0.35	0.13, 0.94	0.25	0.09, 0.74		45	50	51	146	
		97, 98 (don't know/refuse to ans)		0 (0.0%)	1 (1.7%)	0 (0.0%)	1 (0.6%)						
132	does he drink more/less/same as one year ago	more than before	3	1.00(Inf)	1.00(Inf)	0.37	.	.	28	31	31	90	Kappa is fairly low, indicating quite poor inter-observer agreement. This question shows a very clear trend, but the question may have some predictive value. Non-response is zero.
		less than before	c(1,3)	2.95	1.14, 7.67	0.86	2.13, 36.91		24	9	3	36	
		97, 98 (don't know/refuse to ans)		0.68	0.27, 1.69	0.55	0.23, 1.36		11	18	22	51	
		99 (system generated skip)		0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)		0	0	0	0	
				10 (13.7%)	11 (15.9%)	10 (15.2%)	31 (14.9%)		10	11	10	31	146

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments	
				OR	95% CI	OR	95% CI		case proxy	control proxy	control total		
133	does he drink more/less/same as one month ago	about the same more than before less than before	3 c(1,3) c(2,3)	1.00(ref) 22.40 1.60	1.00(ref) 1.64, 305.20 0.48, 5.32	1.00(ref) 16.80, 216.73 1.00, 3.32	1.00(ref) 1.30, 216.73 0.30, 3.32	0.41	1.0 1.4 1.0	1.6 1 1.0	12 1 12	38 1.6 32	Kappa is fairly low, indicating quite poor inter-observer agreement. This question shows a very clear trend, the question may have some predictive value. Non-response is low in all groups.
134	was there any period of being other than during past year	97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00(ref) 0.94	1.00(ref) 0.48, 1.85	1.00(ref) 0.93, 1.84	1.00(ref) 0.47, 1.84	0.58	32 37	30 37	29 36	91 110	The ORs are very close to 1 and not significant. Combined with a middle kappa value, the value of 1.34 is questionable. Non-response is low in all groups.
135	did he ever have professional advice	97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00(ref) 0.38	1.00(ref) 0.16, 0.91	1.00(ref) 0.44, 1.04	1.00(ref) 0.19, 1.04	0.81	21 52	9 59	10 56	40 167	
136	was this advice in past year	97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00(ref) 0.33	1.00(ref) 0.05, 2.12	1.00(ref) 0.33, 2.12	1.00(ref) 0.05, 2.12	1.00	9 12	2 8	2 8	13 28	These questions have very high kappa values indicating good inter-observer agreement, and quite low ORs, although not all are significant. The predictive value of these questions appears quite good. Non-response is low.
137	had he ever gone to a sobering-up centre	97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00(ref) 0.96	1.00(ref) 0.07, 12.38	1.00(ref) 0.95, 12.38	1.00(ref) 0.07, 12.38	-	19 2	9 1	9 1	37 4	No kappa has been calculated for this question due to the low number of population, making categories in the cross-tabulation. ORs are non-significant and close to 1 indicating poor predictive value. Non-response is zero for all groups.
138	was this during past year	97, 98 (don't know/refuse to ans) 99 (system generated skip)	1 c(2,1)	1.00(ref) 0.86	1.00(ref) 0.16, 4.70	1.00(ref) 0.49, 3.21	1.00(ref) 0.07, 3.21	0.71	7 12	3 6	2 7	12 25	This has a high kappa value, indicating good inter-observer agreement, but non-significant OR, mainly close to 1. Again, the can be explained by the low number of responses.

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n			Comments			
				OR	95% CI	OR	95% CI		case proxy	control proxy	control		total		
M1	is he a current smoker?	never a smoker	1	1.00 (ref)	.	1.00 (ref)	.	1.00	3	9	9	21	Kappa is 1 indicating excellent inter-observer agreement. Non-response is 0. There is some evidence of a trend apparent from the ORs, although they are not significant.		
		no, ex-smoker	c(2,1)	2.25	0.39, 12.89	2.57	0.43, 15.26		6	8	7	21			
		yes, current smoker	c(3,1)	3.69	0.93, 14.73	3.84	0.96, 15.37		64	52	50	166			
		97, 98 (don't know/refuse to ans)							0	(0.00%)	0	(0.00%)		0	(0.00%)
		99 (system generated skip)							0	(0.00%)	0	(0.00%)		0	(0.00%)
M2	how many years ago did he stop smoking?	less than 1 year ago	1	1.00 (ref)	.	1.00 (ref)	.	0.86	1	0	0	1	Kappa is very high, indicating very good inter-observer agreement. Due to the low number of respondents for this question (over 88% skipped), it was not possible to calculate ORs.		
		1-5 years ago	c(2,1)	0.00	.	0.00	.		2	4	3	9			
		5-10 years ago	c(3,1)	.	.	0.00	.		0	0	1	1			
		more than 10 years ago	c(4,1)	0.00	.	0.00	.		3	4	3	10			
		97, 98 (don't know/refuse to ans)							0	(0.00%)	0	(0.00%)		0	(0.00%)
99 (system generated skip)								67	(91.76%)	61	(88.41%)	59	(89.39%)	187	(89.90%)
M3	what did he smoke most often?	papyrosi	1	1.00 (ref)	.	1.00 (ref)	.	0.93	9	2	2	13	Kappa is very high, indicating very good inter-observer agreement. There were no responses to categories 4, 5 or 6 - perhaps these should be dropped. Non-response was otherwise low in all groups. Among the other categories, it appears that smoking filtered cigarettes is protective compared with papyrosi.		
		filtered cigarettes	c(2,1)	0.16	0.03, 0.84	0.16	0.03, 0.84		32	45	45	122			
		unfiltered cigarettes	c(3,1)	0.89	0.15, 5.17	1.04	0.17, 6.20		28	7	6	41			
		self-rolled cigarettes	c(4,1)	.	.	.	.		0	0	0	0			
		pipe	c(5,1)	.	.	.	.		0	0	0	0			
		cigars/cigarillos	c(6,1)	.	.	.	.		0	0	0	0		0	
		97, 98 (don't know/refuse to ans)							1	(1.43%)	2	(3.57%)		2	(3.64%)
99 (system generated skip)							3	(4.11%)	13	(18.84%)	11	(16.67%)	27	(12.98%)	

Q	Question text	Comparison strata	strata code	Control proxy		Control		weighted kappa	n				Comments
				OR	95% CI	OR	95% CI		case proxy	control proxy	control	total	
M4	when he smoked, how many per day were usual	1-5 per day	1	1.00 (ref)	.	1.00 (ref)	.	0.67	10	7	5	22	Kappa is high, indicating good inter-observer agreement. There is some evidence of a trend whereby smoking between 6 and 20 cigarettes per day has some protective effect compared with smoking 1-5 per day. Is this plausible? However, the ORs are not significant and the trend is not convincing. Non-response is higher in proxies than controls, indicating this question may be difficult for proxies to answer.
		6-10 per day	c(2,1)	0.65	0.18, 2.29	0.46	0.12, 1.82		12	13	13	38	
		11-20 per day	c(3,1)	0.67	0.22, 2.09	0.43	0.12, 1.47		23	24	27	74	
		more than 20 per day	c(4,1)	1.63	0.46, 5.78	1.05	0.28, 3.95		21	9	10	40	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							4 (5.71%)	7 (11.67%)	2 (3.51%)	13 (6.95%)	
M5	how old was he when he started smoking properly	<10 years old	1	1.00 (ref)	.	1.00 (ref)	.	0.77	4	1	2	7	Kappa is high, indicating good inter-observer agreement. It appears that starting smoking at older ages is protective, although again, ORs are not significant. Non-response is much higher in proxies than controls.
		10-19 years old	c(2,1)	0.32	0.03, 3.11	0.60	0.10, 3.54		37	29	31	97	
		20-29 years old	c(3,1)	0.26	0.03, 2.75	0.45	0.07, 2.85		20	19	22	61	
		>30 years old	c(4,1)	0.00	.	0.00	.		0	1	1	2	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							9 (12.86%)	10 (16.67%)	0 (0.00%)	19 (10.22%)	
M6	did either parent smoke	neither	4	1.00 (ref)	.	1.00 (ref)	.	0.76	41	48	49	138	Kappa is high, indicating good inter-observer agreement. The low number of responses prevented calculation of ORs for most strata, so it is difficult to determine any trend. Non-response is high among proxies, as expected for a question of this nature.
		father only	c(1,4)	0.67	0.27, 1.65	0.66	0.27, 1.62		0	2	1	3	
		mother only	c(2,4)	0.00	.	0.00	.		7	0	1	8	
		both parents	c(3,4)	.	.	5.50	0.51, 58.78		14	11	11	36	
		97, 98 (don't know/refuse to ans) 99 (system generated skip)							11 (14.47%)	8 (10.26%)	4 (5.26%)	23 (10.00%)	
								0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)		

## **Appendix 5**

### **External data collection forms**



**Code Description****Narcology Dispensary data**

narc1	Interim Individual identification number
narc2	Individual identification number
narc3	Date of registration in the Dispensary, Year
narc4	Date of registration in the Dispensary, Month
narc5	Date of registration in the Dispensary, Day
narc6	The main diagnosis on entry in a text form
narc7	Code of the main diagnosis
narc8	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 1
narc9	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 2
narc10	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 3
narc11	ICD-codes of the accompanying diagnoses (up to 3 codes), 1
narc12	ICD-codes of the accompanying diagnoses (up to 3 codes), 2
narc13	ICD-codes of the accompanying diagnoses (up to 3 codes), 3
narc14	Date of the last contact, Year
narc15	Date of the last contact, Month
narc16	Date of the last contact, Day
narc17	The main diagnosis after the last contact
narc18	Code of the main diagnosis
narc19	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 1

<b>Code</b>	<b>Description</b>
narc20	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 2
narc21	Accompanying alcohol-related pathologies in a text form (up to 3 diagnoses), 3
narc22	ICD-codes of the accompanying diagnoses (up to 3 codes), 1
narc23	ICD-codes of the accompanying diagnoses (up to 3 codes), 2
narc24	ICD-codes of the accompanying diagnoses (up to 3 codes), 3
narc25	Date completing
<b>Social Security data</b>	
SS1	Individual identification number
SS2	# in SOBES list
SS3	Registration number
SS4	Family Name (write in words)
SS5	First Name (Write in words)
SS6	Second Name (Father's Name) (Write in words)
SS7	Data of birth (number)
SS8	Area code
SS9	Area
SS10	Place of permanent residence in Izhevsk (street)
SS11	Place of permanent residence in Izhevsk (house)
SS12	Place of permanent residence in Izhevsk (building)
SS13	Place of permanent residence in Izhevsk (apartment)

<b>Code</b>	<b>Description</b>
SS14	Date of registration of invalidity
SS15	Group of invalidity
SS16	Date of registration of death
SS17	Date of death

**Police records**

pol1	Family Name (write in words)
pol2	First Name (Write in words)
pol3	Second Name (Father's Name) (Write in words)
pol4	Date of birth
pol5	Place of birth
pol6	Place of permanent residence in Izhevsk (street)
pol7	Place of permanent residence in Izhevsk (house)
pol8	Place of permanent residence in Izhevsk (apartment)
pol9	Individual identification number
pol10	Mark "x" if the person was in prison
pol11	Prison stay 1 from (year)
pol12	to (year)
pol13	Prison stay 2 from (year)
pol14	to (year)
pol15	Prison stay 3 from (year)

<b>Code</b>	<b>Description</b>
pol16	to (year)
pol17	Prison stay 4 from (year)
pol18	to (year)
pol19	Prison stay 5 from (year)
pol20	to (year)
pol21	Prison stay 6 from (year)
pol22	to (year)
pol23	Prison stay 7 from (year)
pol24	to (year)
pol25	Number of prison stays
pol26	Date of last stay
<b>Autopsy data</b>	
aut1	Running number
aut2	Name
aut3	Forename
aut4	Patronymic
aut5	Date of birth, Year
aut6	Date of birth, Month
aut7	Date of birth, Day
aut8	Place of permanent residence in Izhevsk, Street

<b>Code</b>	<b>Description</b>
aut9	Place of permanent residence in Izhevsk, House
aut10	Place of permanent residence in Izhevsk, Apartment
aut11	Estimated date of death, Year
aut12	Estimated date of death, Month
aut13	Estimated date of death, Day
aut14	Estimated time of death, Hour
aut15	Estimated time of death, Minute
aut16	Place of death
aut17	Site of death: 1-hospital, 2 - home, 3- other place,
aut18	Place of autopsy
aut19	Whether it was a forensic or non-forensic autopsy
aut20	Data of autopsy, Year
aut21	Data of autopsy, Month
aut22	Data of autopsy, Day
aut23	Time of autopsy, Hour
aut24	Time of autopsy, Minute
aut25	The name of the pathologist who did the autopsy
aut26	The number of the case/autopsy as used by the pathologists in their own record system
aut27	Number of the medical death certificate
aut28	ongoing police investigation

<b>Code</b>	<b>Description</b>
aut29	Causes of death, a) Immediate cause
aut30	Causes of death, Code
aut31	Causes of death, b) Intermediate cause
aut32	Causes of death, Code
aut33	Causes of death, c) Main cause
aut34	Causes of death, Code
aut35	Causes of death, External causes
aut36	Causes of death, Code
aut37	Causes of death, Other important diseases
aut38	Concentration of alcohol in blood , Code
aut39	Concentration of alcohol in blood
aut40	Concentration of alcohol in urine
aut41	Disease and pathological processes connected with alcohol
aut42	The text description of circumstances surrounding the death
aut43	Name of person completing the form
aut44	Date completing the form, Year
aut45	Date completing the form, Month
aut46	Date completing the form, Day
aut47	ID. Provided by Medical academy

## **Appendix 6**

### **Distribution of responses by respondent type in the main sample**

Q	Question text	Comparison strata	case proxy	control proxy	control	total
			n %	n %	n %	n %
	<b>TOTAL</b>		1,305 100.0%	1,140 100.0%	1,140 100.0%	3,585 100.0%
L1	How often is beer usually drunk	every day or more often	43 3.3%	15 1.3%	10 0.9%	68 1.9%
		nearly every day	127 9.7%	64 5.6%	49 4.3%	240 6.7%
		three or four times a week	116 8.9%	112 9.8%	90 7.9%	318 8.9%
		once or twice a week	284 21.8%	297 26.1%	332 29.1%	913 25.5%
		1-3 times a month	240 18.4%	274 24.0%	263 23.1%	777 21.7%
		a few times per year	87 6.7%	85 7.5%	86 7.5%	258 7.2%
		never or almost never	376 28.8%	283 24.8%	310 27.2%	969 27.0%
		difficult to answer	30 2.3%	9 0.8%	0 0.0%	39 1.1%
		refuse to answer	2 0.2%	1 0.1%	0 0.0%	3 0.1%
		no answer	0 0.0%	0 0.0%	0 0.0%	0 0.0%
L2	How often is wine usually drunk	every day or more often	19 1.5%	4 0.4%	0 0.0%	23 0.6%
		nearly every day	66 5.1%	7 0.6%	3 0.3%	76 2.1%
		three or four times a week	58 4.4%	13 1.1%	8 0.7%	79 2.2%
		once or twice a week	77 5.9%	52 4.6%	51 4.5%	180 5.0%
		1-3 times a month	153 11.7%	142 12.5%	119 10.4%	414 11.5%
		a few times per year	125 9.6%	213 18.7%	210 18.4%	548 15.3%
		never or almost never	769 58.9%	697 61.1%	749 65.7%	2215 61.8%
		difficult to answer	36 2.8%	11 1.0%	0 0.0%	47 1.3%
		refuse to answer	2 0.2%	1 0.1%	0 0.0%	3 0.1%
		no answer	0 0.0%	0 0.0%	0 0.0%	0 0.0%
L3	How often are spirits usually drunk	every day or more often	42 3.2%	4 0.4%	3 0.3%	49 1.4%
		nearly every day	120 9.2%	29 2.5%	20 1.8%	169 4.7%
		three or four times a week	134 10.3%	59 5.2%	31 2.7%	224 6.2%
		once or twice a week	250 19.2%	206 18.1%	252 22.1%	708 19.7%
		1-3 times a month	340 26.1%	342 30.0%	370 32.5%	1052 29.3%
		a few times per year	156 12.0%	251 22.0%	227 19.9%	634 17.7%
		never or almost never	226 17.3%	240 21.1%	236 20.7%	702 19.6%
		difficult to answer	34 2.6%	8 0.7%	1 0.1%	43 1.2%
		refuse to answer	3 0.2%	1 0.1%	0 0.0%	4 0.1%
		no answer	0 0.0%	0 0.0%	0 0.0%	0 0.0%
L4	How often are other alcoholic substances drunk	every day or more often	114 8.7%	6 0.5%	0 0.0%	120 3.3%
		nearly every day	189 14.5%	15 1.3%	10 0.9%	214 6.0%
		three or four times a week	73 5.6%	13 1.1%	10 0.9%	97 2.7%
		once or twice a week	77 5.9%	18 1.6%	13 1.1%	108 3.0%
		1-3 times a month	44 3.4%	26 2.3%	22 1.9%	92 2.6%
		a few times per year	29 2.2%	14 1.2%	17 1.5%	60 1.7%
		never or almost never	746 57.2%	1033 90.6%	1067 93.6%	2846 79.4%
		difficult to answer	31 2.4%	14 1.2%	0 0.0%	45 1.3%
		refuse to answer	2 0.2%	1 0.1%	0 0.0%	3 0.1%
		no answer	0 0.0%	0 0.0%	0 0.0%	0 0.0%



Q	Question text	Comparison strata	case proxy	control proxy	control	total
L5	On which day is beer usually drunk	only at the weekend	122	271	284	677
		only on week days	8	7	11	26
		any day	673	490	465	1628
		every day	44	18	16	78
		only on holidays/celebration	55	59	50	164
		never or almost never	269	131	156	556
		difficult to answer	19	9	2	30
		refuse to answer	1	0	0	1
		no answer	114	155	156	425
L6	On which day is wine usually drunk	only at the weekend	36	67	59	162
		only on week days	3	2	2	7
		any day	313	118	113	544
		every day	19	3	1	23
		only on holidays/celebration	129	241	217	587
		never or almost never	656	544	589	1789
		difficult to answer	34	10	3	47
		refuse to answer	1	0	0	1
		no answer	114	155	156	425
L7	On which day are spirits usually drunk	only at the weekend	138	206	275	619
		only on week days	10	8	7	25
		any day	684	296	268	1248
		every day	47	14	7	68
		only on holidays/celebration	171	370	346	887
		never or almost never	116	87	80	283
		difficult to answer	24	4	1	29
		refuse to answer	1	0	0	1
		no answer	114	155	156	425
L8	On which day are other alcoholic substances usually drunk	only at the weekend	13	8	11	32
		only on week days	5	1	2	8
		any day	383	71	51	505
		every day	116	4	2	122
		only on holidays/celebration	3	0	1	4
		never or almost never	639	865	915	2439
		difficult to answer	32	15	2	49
		refuse to answer	0	1	0	1
		no answer	114	155	156	425

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L9	How much beer is usually drunk on one occasion	never drank beer	265	129	155	549
		1 bottle or less	474	506	440	1420
		2-4 bottles	335	300	369	1004
		5-6 bottles	9	14	14	37
		more than 6 bottles	14	3	2	19
		difficult to answer	91	33	4	128
		refuse to answer	2	0	0	2
		no answer	115	155	156	426
		never drank wine	661	545	589	1795
		up to 200g	122	151	115	388
L10	How much wine is usually drunk on one occasion	between 200 - 400g	151	164	180	495
		between 400 - 600g	73	49	56	178
		between 600 - 1000g	66	27	39	132
		more than 1 litre	20	7	4	31
		difficult to answer	96	42	1	139
		refuse to answer	1	0	0	1
		no answer	115	155	156	426
		never drank spirits	112	88	78	278
		between 50 - 100g	107	103	84	294
		between 100 - 200g	210	224	251	685
L11	What quantity of spirits is usually drunk on one occasion	between 200 - 300g	311	307	343	961
		between 300 - 400g	63	46	88	197
		between 400 - 500g	203	122	111	436
		more than 500g	70	18	27	115
		difficult to answer	113	77	2	192
		refuse to answer	1	0	0	1
		no answer	115	155	156	426
		never drank spirits	112	88	78	278
		between 50 - 100g	107	103	84	294
		between 100 - 200g	210	224	251	685
between 200 - 300g	311	307	343	961		
between 300 - 400g	63	46	88	197		
between 400 - 500g	203	122	111	436		
more than 500g	70	18	27	115		
difficult to answer	113	77	2	192		
refuse to answer	1	0	0	1		
no answer	115	155	156	426		

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L12	What is the maximum quantity of beer ever drunk on one occasion	never drank beer	261	127	156	544
		1 bottle or less	230	210	174	614
		2-4 bottles	454	452	463	1369
		5-6 bottles	79	80	133	292
		more than 6 bottles	31	31	51	112
		difficult to answer	135	85	6	226
		refuse to answer	1	0	1	2
		no answer	115	155	156	426
		never drank wine	659	544	588	1791
		up to 200g	57	65	45	167
L13	What is the maximum quantity of wine ever drunk on one occasion	between 200 - 400g	112	144	123	379
		between 400 - 600g	83	78	99	260
		between 600 - 1000g	115	64	96	275
		more than 1 litre	62	24	26	112
		difficult to answer	101	66	7	174
		refuse to answer	1	0	0	1
		no answer	115	155	156	426
		never drank spirits	112	86	75	273
		between 50 - 100g	44	34	25	103
		between 100 - 200g	102	105	81	288
L14	What are the maximum quantity of spirits ever drunk on one occasion	between 200 - 300g	178	190	183	551
		between 300 - 400g	82	94	140	316
		between 400 - 500g	290	238	299	827
		more than 500g	253	131	169	553
		difficult to answer	128	107	11	246
		refuse to answer	1	0	1	2
		no answer	115	155	156	426
		never drank spirits	112	86	75	273
		between 50 - 100g	44	34	25	103
		between 100 - 200g	102	105	81	288
between 200 - 300g	178	190	183	551		
between 300 - 400g	82	94	140	316		
between 400 - 500g	290	238	299	827		
more than 500g	253	131	169	553		
difficult to answer	128	107	11	246		
refuse to answer	1	0	1	2		
no answer	115	155	156	426		

Q	Question text	Comparison strata	case proxy	control proxy	control	total		
L15	Does he ever drink spirits together with either beer or wine at the same sitting	yes, often	148	37	21	206		
		yes, sometimes	411	374	380	1165		
		no, never	535	536	583	1654		
		difficult to answer	96	38	0	134		
L16	Does he ever drink large quantities of spirits without also eating some food	refuse to answer	0	0	0	0		
		no answer	115	155	156	426		
		often	192	29	10	231		
		sometimes	342	175	132	649		
L17	How often does he become excessively drunk	rarely/never	590	755	841	2186		
		difficult to answer	66	26	0	92		
		refuse to answer	0	0	1	1		
		no answer	115	155	156	426		
L18	Does he ever drink alcohol before noon	every day	144	12	4	160		
		several times a week	196	39	10	245		
		once a week	84	42	25	151		
		several times a month	137	58	35	230		
		once a month	132	123	128	383		
		less than once a month	141	244	258	643		
		never or almost never	337	459	517	1313		
		difficult to answer	17	8	6	31		
		refuse to answer	2	0	1	3		
		no answer	115	155	156	426		
		L19	How often does he have a hangover	no	455	683	700	1838
				yes, occasionally	400	260	276	936
yes, frequently	311			32	7	350		
difficult to answer	24			10	1	35		
refuse to answer	0			0	0	0		
no answer	115			155	156	426		
every day	164			13	6	183		
several times a week	189			33	15	237		
about once a week	71			29	19	119		
several times a month	116			68	52	236		
about once a month	109			113	138	360		
less than once a month	120			199	229	548		
never or almost never	373	505	516	1394				
difficult to answer	47	25	8	80				
refuse to answer	1	0	1	2				
no answer	115	155	156	426				

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L20	How often does he fail to fulfil his work obligations due to drinking alcohol	every day	5	3	1	9
		several times a week	20	5	0	25
		about once a week	9	6	1	16
		several times a month	30	9	2	41
		about once a month	20	17	14	51
		less than once a month	61	30	34	125
		never	459	782	808	2049
		not applicable	567	129	123	819
		difficult to answer	19	4	1	24
		refuse to answer	0	0	0	0
L21	How often does he fail to fulfil his family or personal obligations due to drinking alcohol	no answer	115	155	156	426
		every day	126	11	3	140
		several times a week	162	29	9	200
		about once a week	44	28	8	80
		several times a month	78	40	16	134
		about once a month	59	74	59	192
		less than once a month	62	76	96	234
		never	600	717	770	2087
		difficult to answer	57	10	20	87
		refuse to answer	2	0	3	5
L22	Does he ever go to sleep at night without taking his clothes off because of being drunk	no answer	115	155	156	426
		every day	108	5	1	114
		several times a week	183	29	4	216
		about once a week	56	17	8	81
		several times a month	104	30	13	147
		about once a month	77	61	40	178
		less than once a month	85	97	86	268
		never or almost never	562	745	830	2137
		difficult to answer	15	1	1	17
		refuse to answer	0	0	1	1
L23	Does he ever drink alone	no answer	115	155	156	426
		yes, often	388	95	50	533
		yes, sometimes	372	355	418	1145
		no, never	403	521	516	1440
		difficult to answer	27	14	0	41
		refuse to answer	0	0	0	0
		no answer	115	155	156	426
		usually at home	478	344	284	1,106
		sometimes at home, sometimes elsewhere	557	511	574	1,642
		usually elsewhere	151	127	126	404
L24	Does he usually drink alcohol at home or in other places	difficult to answer	4	3	0	7
		refuse to answer	0	0	0	0
		no answer	115	155	156	426

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L25	Has he had one or more episodes of zepoi in the past year	yes, often	332	39	18	389
		yes, sometimes	183	83	67	333
		no, never	668	862	896	2426
		difficult to answer	6	1	2	9
L26	Has he had one or more episodes of zepoi in the past month	refuse to answer	1	0	1	2
		no answer	115	155	156	426
		yes	376	65	40	481
		no	134	56	45	235
L27	Has he had one or more episodes of zepoi in the past week	difficult to answer	5	1	0	6
		refuse to answer	0	0	0	0
		no answer	790	1018	1055	2863
		yes	279	30	17	326
		no	87	35	23	145
		difficult to answer	10	0	0	10
		refuse to answer	0	0	0	0
		no answer	929	1075	1100	3104
			25.4%	3.4%	1.6%	10.9%
			14.0%	7.3%	5.9%	9.3%
			51.2%	75.6%	78.6%	67.7%
			0.5%	0.1%	0.2%	0.3%
			0.1%	0.0%	0.1%	0.1%
			8.8%	13.6%	13.7%	11.9%
			28.8%	5.7%	3.5%	13.4%
			10.3%	4.9%	3.9%	6.6%
			0.4%	0.1%	0.0%	0.2%
			0.0%	0.0%	0.0%	0.0%
			60.5%	89.3%	92.5%	79.9%
			21.4%	2.6%	1.5%	9.1%
			6.7%	3.1%	2.0%	4.0%
			0.8%	0.0%	0.0%	0.3%
			0.0%	0.0%	0.0%	0.0%
			71.2%	94.3%	96.5%	86.6%

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L28	During his most recent period of heavy drinking, what was the maximum quantity of beer drunk	none	169	11	9	189
		1 bottle or less	13.0%	1.0%	0.8%	5.3%
		2-4 bottles	14	4	1	19
		5-6 bottles	22	2	5	29
		more than 6 bottles	3	1	0	4
		drank beer, but not sure of the quantity	4	2	1	7
		difficult to answer	29	3	0	32
		refuse to answer	38	7	1	46
		no answer	1026	0	0	0
				1,110	1,123	3,259
L29	During his most recent period of heavy drinking, what was the maximum quantity of wine drunk	never drank wine	199	18	12	229
		up to 200g	2	0	0	2
		between 200 - 400g	6	0	0	6
		between 400 - 600g	5	1	1	7
		between 600 - 1000g	5	0	2	7
		more than 1 litre	5	1	1	7
		drank wine, but not sure of the quantity	28	5	1	34
		difficult to answer	29	2	0	34
		refuse to answer	0	0	0	0
				1,026	1,110	3,259
L30	During his most recent period of heavy drinking, what was the maximum quantity of spirits drunk	none	87	3	4	94
		between 50 - 100g	3	0	0	3
		between 100 - 200g	4	0	0	4
		between 200 - 300g	16	3	3	22
		between 300 - 400g	8	1	0	9
		between 400 - 500g	31	4	5	40
		more than 500g	38	6	3	47
		drank spirits, but not sure of the quantity	70	8	2	80
		difficult to answer	22	5	0	27
		refuse to answer	0	0	0	0
		1,026	1,110	3,259		
L31	During his most recent period of heavy drinking, did he drink any other alcoholic substances	no answer	214	18	9	241
		yes	16.4%	1.6%	0.8%	6.7%
		no	57	10	8	75
		difficult to answer	8	2	0	10
		refuse to answer	0	0	0	0
		no answer	1026	1110	1123	3259
		yes	212	67	69	348
		no	958	905	915	2778
		difficult to answer	20	13	0	33
		refuse to answer	0	0	0	0
		115	155	426		
L32	Has he been arrested because of being drunk during the past year	no answer	115	155	156	426
		8.8%	13.6%	13.7%	11.9%	

Q	Question text	Comparison strata	case proxy	control proxy	control	total
L33	Does he currently drink more, less or about the same as one year ago	more than a year before	349	124	61	534
		about the same as a year before	451	557	546	1,554
		less than a year before	368	291	370	1,029
L34	Does he currently drink more, less or the same as one month ago	difficult to answer	21	13	6	40
		refuse to answer	1	0	1	2
		no answer	115	155	156	426
L35	Has there been any period when he drank heavily other than during the past 12 months	more than a month before	194	32	27	253
		about the same as a month before	555	709	703	1,967
		less than a month before	400	229	236	865
L36	Has he ever had help or advice from a doctor, neurologist, social worker or some other professional for an alcohol problem	difficult to answer	40	15	17	72
		refuse to answer	1	0	1	2
		no answer	115	155	156	426
L37	Did he get such help during the past year	yes	631	468	475	1,574
		no	621	638	658	1,917
		difficult to answer	53	34	7	94
L38	Has he ever been taken to a sobering up centre	refuse to answer	0	0	0	0
		no answer	0	0	0	0
		yes	401	166	162	729
L39	Was this during the past year	no	886	965	978	2,829
		difficult to answer	18	9	0	27
		refuse to answer	0	0	0	0
L39	Was this during the past year	no answer	0	0	0	0
		yes	128	30	28	186
		difficult to answer	271	135	134	540
L38	Has he ever been taken to a sobering up centre	refuse to answer	2	1	0	3
		no answer	0	0	0	0
		yes	904	974	978	2,856
L39	Was this during the past year	no	792	495	557	1,844
		difficult to answer	450	610	581	1,641
		refuse to answer	62	35	1	98
L39	Was this during the past year	no answer	1	0	1	2
		yes	222	84	78	384
		difficult to answer	540	402	479	1,421
L39	Was this during the past year	refuse to answer	30	9	0	39
		no answer	0	0	0	0
		yes	513	645	583	1,741



Q	Question text	Comparison strata	case proxy	control proxy	control	total
M1	Is he a current smoker	never a smoker	96	235	217	548
		no, ex-smoker	118	148	164	430
M2	How many years ago did he stop smoking regularly	yes, a current-smoker	1091	757	758	2606
		difficult to answer	0	0	1	1
		refuse to answer	0	0	0	0
		no answer	0	0	0	0
		less than one year before death	44	20	21	85
		>1 year, < 5 years before death	24	21	23	68
		>5 years, < 10 years before death	12	34	36	82
		more than 10 years before death	37	73	84	194
		difficult to answer	1	0	0	1
		refuse to answer	0	0	0	0
M3	What does he smoke most often (other)	no answer	1187	992	976	3155
		pepyrosi	44	17	18	79
		filtered cigarettes	754	740	776	2270
		unfiltered cigarettes	370	108	117	595
		other (specify)	17	4	10	31
		difficult to answer	24	36	1	61
		refuse to answer	0	0	0	0
		no answer	96	235	218	549
		1-5 per day	98	80	65	243
		6-10 per day	214	149	178	541
M4	When he smoked, how many per day was usual	11-20 per day	561	421	534	1516
		more than 20 per day	221	109	142	472
		difficult to answer	115	146	3	264
		refuse to answer	0	0	0	0
		no answer	96	235	218	549
		<10 years old	19	9	15	43
		10-19 years old	665	439	553	1657
		20-29 years old	298	242	317	857
		>30 years old	25	27	33	85
		difficult to answer	202	188	4	394
M5	How old he started smoking regularly	refuse to answer	0	0	0	0
		no answer	96	235	218	549
		<10 years old	19	9	15	43
		10-19 years old	665	439	553	1657
		20-29 years old	298	242	317	857
		>30 years old	25	27	33	85
		difficult to answer	202	188	4	394
		refuse to answer	0	0	0	0
		no answer	96	235	218	549
		yes, father only	773	654	772	2199
M6	Have his parents ever smoked	yes, mother only	6	7	8	21
		yes, both parents	32	17	22	71
		no, neither	281	280	293	854
		difficult to answer	213	182	45	440
		refuse to answer	0	0	0	0
		no answer	0	0	0	0

Q	Question text	Comparison strata	case proxy	control proxy	control	total
E15	What is his marital status?	living with registered spouse	702	887	890	2479
		living with unregistered spouse	157	121	115	393
		divorced/separated	245	65	69	379
		widower	42	8	6	56
		never married	159	59	60	278
		difficult to answer	0	0	0	0
F1	What is his level of education?	refuse to answer	0	0	0	0
		no answer	0	0	0	0
		some/complete secondary	572	409	449	1430
		professional school	330	205	182	717
		specialised secondary	245	261	254	760
		some/complete higher	137	255	254	646
F3	Is he in regular paid employment?	difficult to answer	21	10	1	32
		refuse to answer	0	0	0	0
		no answer	0	0	0	0
		yes	516	947	949	2412
		no, for reasons unrelated to ill health	410	135	135	680
		no, due to invalidity	307	46	47	400
C14	Does his household own a car?	no, for reasons related to ill health	71	11	8	90
		difficult to answer	1	0	1	2
		refuse to answer	0	1	0	1
		no answer	0	0	0	0
		yes	303	527	549	1379
		no	1002	613	591	2206
J8	Is he registered disabled?	difficult to answer	0	0	0	0
		refuse to answer	0	0	0	0
		no answer	0	0	0	0
		yes	374	71	71	516
		no	928	1069	1069	3066
		difficult to answer	0	0	0	0

Q	Question text	Comparison strata	case proxy	control proxy	control	total	
K1	Has he had any broken bones in the past year?	yes	131	53	53	237	
		no	1168	1087	1087	3342	
		difficult to answer	6	0	0	6	
		refuse to answer	0	0	0	0	
K2	Does he usually cough in the morning?	no answer	0	0	0	0	
		often	582	323	219	1124	
		sometimes	217	236	225	678	
		rarely	81	91	117	289	
		never	407	479	577	1463	
		difficult to answer	18	11	1	30	
K3	In the past few months, could he climb up a flight up of stairs without becoming breathless?	refuse to answer	0	0	0	1	
		no answer	0	0	0	0	
		yes, easily	680	975	1027	2682	
		yes, with some difficulty	324	111	94	529	
		no, too difficult	259	15	14	288	
		difficult to answer	42	39	5	86	
		refuse to answer	0	0	0	0	
		no answer	0	0	0	0	

## **Appendix 7**

### **Distribution of analysed responses to validation interview questions by respondent type**

Q	Question text	Response category	CASES						CONTROLS							
			PROXY1		PROXY2		PROXY1		PROXY2		PROXY1		PROXY2		CONTROL	
			N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0	178	100.0
L1	How often is beer usually drunk	every day or more often	2	1.5%	1	0.8%	3	1.7%	0	0.0%	2	1.1%	2	1.1%		
		nearly every day	13	9.9%	9	6.9%	8	4.5%	7	3.9%	2	1.1%				
		three or four times a week	7	5.3%	9	6.9%	16	9.0%	12	6.7%	17	9.6%				
		once or twice a week	30	22.9%	29	22.1%	43	24.2%	44	24.7%	37	20.8%				
		1-3 times a month	30	22.9%	31	23.7%	52	29.2%	53	29.8%	44	24.7%				
		a few times per year	9	6.9%	10	7.6%	13	7.3%	13	7.3%	16	9.0%				
		never or almost never	39	29.8%	38	29.0%	42	23.6%	46	25.8%	46	25.8%				
		difficult to answer	1	0.8%	4	3.1%	1	0.6%	3	1.7%	0	0.0%				
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
L2	How often is wine usually drunk	every day or more often	2	1.5%	2	1.5%	2	1.1%	2	1.1%	0	0.0%				
		nearly every day	9	6.9%	5	3.8%	2	1.1%	1	0.6%	0	0.0%				
		three or four times a week	5	3.8%	4	3.1%	1	0.6%	2	1.1%	3	1.7%				
		once or twice a week	10	7.6%	7	5.3%	6	3.4%	2	1.1%	5	2.8%				
		1-3 times a month	19	14.5%	16	12.2%	23	12.9%	21	11.8%	15	8.4%				
		a few times per year	9	6.9%	19	14.5%	32	18.0%	31	17.4%	30	16.9%				
		never or almost never	74	56.5%	76	58.0%	110	61.8%	115	64.6%	111	62.4%				
		difficult to answer	3	2.3%	2	1.5%	2	1.1%	4	2.2%	0	0.0%				
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%				
L3	How often are spirits usually drunk	every day or more often	4	3.1%	2	1.5%	1	0.6%	1	0.6%	1	0.6%				
		nearly every day	8	6.1%	8	6.1%	4	2.2%	7	3.9%	3	1.7%				
		three or four times a week	14	10.7%	11	8.4%	7	3.9%	4	2.2%	6	3.4%				
		once or twice a week	22	16.8%	27	20.6%	44	24.7%	32	18.0%	44	24.7%				
		1-3 times a month	37	28.2%	36	27.5%	56	31.5%	57	32.0%	53	29.8%				
		a few times per year	23	17.6%	26	19.8%	28	15.7%	35	19.7%	20	11.2%				
		never or almost never	20	15.3%	19	14.5%	36	20.2%	40	22.5%	37	20.8%				
		difficult to answer	3	2.3%	2	1.5%	2	1.1%	2	1.1%	0	0.0%				
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%				

Q	Question text	Response category	CASES			CONTROLS						
			PROXY1	PROXY2	PROXY1	PROXY2	CONTROL					
			N	%	N	%	N	%				
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0		
L4	How often are other alcoholic substances drunk	every day or more often	13	9.9%	8	6.1%	3	1.7%	1	0.6%	0	0.0%
		nearly every day	19	14.5%	23	17.6%	3	1.7%	3	1.7%	1	0.6%
		three or four times a week	4	3.1%	1	0.8%	1	0.6%	5	2.8%	3	1.7%
		once or twice a week	9	6.9%	11	8.4%	0	0.0%	1	0.6%	1	0.6%
		1-3 times a month	5	3.8%	1	0.8%	4	2.2%	3	1.7%	2	1.1%
		a few times per year	2	1.5%	4	3.1%	3	1.7%	0	0.0%	3	1.7%
		never or almost never	79	60.3%	79	60.3%	159	89.3%	164	92.1%	154	86.5%
		difficult to answer	0	0.0%	4	3.1%	5	2.8%	1	0.6%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
L5	On which day is beer usually drunk	only at the weekend	14	10.7%	18	13.7%	40	22.5%	39	21.9%	35	19.7%
		only on week days	1	0.8%	0	0.0%	0	0.0%	1	0.6%	1	0.6%
		any day	65	49.6%	60	45.8%	82	46.1%	71	39.9%	71	39.9%
		every day	6	4.6%	5	3.8%	4	2.2%	1	0.6%	3	1.7%
		only on holidays/celebration	5	3.8%	5	3.8%	9	5.1%	18	10.1%	7	3.9%
		never or almost never	27	20.6%	27	20.6%	19	10.7%	20	11.2%	24	13.5%
		difficult to answer	1	0.8%	4	3.1%	0	0.0%	1	0.6%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%
					4	3.1%	1	0.8%	6	3.4%	5	2.8%
L6	On which day is wine usually drunk	only at the weekend	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		only on week days	34	26.0%	29	22.1%	23	12.9%	15	8.4%	19	10.7%
		any day	2	1.5%	3	2.3%	2	1.1%	1	0.6%	0	0.0%
		every day	14	10.7%	19	14.5%	34	19.1%	39	21.9%	31	17.4%
		only on holidays/celebration	62	47.3%	64	48.9%	88	49.4%	89	50.0%	88	49.4%
		never or almost never	3	2.3%	3	2.3%	1	0.6%	2	1.1%	0	0.0%
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		refuse to answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%
		no answer										

Q	Question text	Response category	CASES						CONTROLS							
			PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2				
			N	%	N	%	N	%	N	%	N	%	N	%		
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0		
L7	On which day are spirits usually drunk	only at the weekend	16	12.2%	12	9.2%	30	16.9%	23	12.9%	41	23.0%				
		only on week days	1	0.8%	0	0.0%	3	1.7%	4	2.2%	1	0.6%				
		any day	64	48.9%	62	47.3%	51	28.7%	44	24.7%	44	24.7%				
		every day	3	2.3%	5	3.8%	2	1.1%	2	1.1%	2	1.1%				
		only on holidays/celebration	24	18.3%	31	23.7%	55	30.9%	62	34.8%	39	21.9%				
		never or almost never	8	6.1%	7	5.3%	13	7.3%	14	7.9%	14	7.9%				
		difficult to answer	3	2.3%	2	1.5%	0	0.0%	2	1.1%	0	0.0%				
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		no answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%				
				only at the weekend	1	0.8%	1	0.8%	1	0.6%	0	0.0%	0	0.0%		
L8	On which day are other alcoholic substances usually drunk	only on week days	1	0.8%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		any day	31	23.7%	23	17.6%	12	6.7%	12	6.7%	8	4.5%				
		every day	16	12.2%	20	15.3%	2	1.1%	1	0.6%	0	0.0%				
		only on holidays/celebration	2	1.5%	2	1.5%	0	0.0%	0	0.0%	0	0.0%				
		never or almost never	68	51.9%	68	51.9%	137	77.0%	138	77.5%	133	74.7%				
		difficult to answer	0	0.0%	5	3.8%	2	1.1%	0	0.0%	0	0.0%				
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
		no answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%				
				never drank beer	27	20.6%	27	20.6%	19	10.7%	20	11.2%	24	13.5%		
		L9	How much beer is usually drunk on one occasion	1 bottle or less	58	44.3%	45	34.4%	84	47.2%	78	43.8%	72	40.4%		
2-4 bottles	29			22.1%	34	26.0%	42	23.6%	45	25.3%	42	23.6%				
5-6 bottles	1			0.8%	2	1.5%	3	1.7%	0	0.0%	1	0.6%				
more than 6 bottles	0			0.0%	1	0.8%	1	0.6%	2	1.1%	1	0.6%				
difficult to answer	4			3.1%	10	7.6%	5	2.8%	6	3.4%	1	0.6%				
refuse to answer	0			0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%				
no answer	12			9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%				

Q	Question text	Response category	CASES				CONTROLS						
			PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2	CONTROL				
			N	%	N	%	N	%	N	%	N	%	
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	
L10	How much wine is usually drunk on one occasion	never drank wine	64	48.9%	65	49.6%	88	49.4%	90	50.6%	88	49.4%	
		up to 200g	15	11.5%	14	10.7%	23	12.9%	29	16.3%	18	10.1%	
		between 200 - 400g	21	16.0%	18	13.7%	27	15.2%	21	11.8%	19	10.7%	
		between 400 - 600g	5	3.8%	5	3.8%	6	3.4%	3	1.7%	9	5.1%	
		between 600 - 1000g	8	6.1%	7	5.3%	5	2.8%	1	0.6%	6	3.4%	
		more than 1 litre	3	2.3%	1	0.8%	1	0.6%	2	1.1%	1	0.6%	
		difficult to answer	3	2.3%	9	6.9%	4	2.2%	5	2.8%	0	0.0%	
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	
		no answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	
					8	6.1%	7	5.3%	13	7.3%	14	7.9%	14
L11	What quantity of spirits is usually drunk on one occasion	never drank spirits	22	16.8%	14	10.7%	23	12.9%	26	14.6%	11	6.2%	
		between 50 - 100g	27	20.6%	20	15.3%	35	19.7%	27	15.2%	36	20.2%	
		between 100 - 200g	19	14.5%	26	19.8%	47	26.4%	37	20.8%	43	24.2%	
		between 200 - 300g	8	6.1%	8	6.1%	5	2.8%	11	6.2%	15	8.4%	
		between 300 - 400g	21	16.0%	23	17.6%	18	10.1%	16	9.0%	19	10.7%	
		between 400 - 500g	6	4.6%	6	4.6%	5	2.8%	2	1.1%	3	1.7%	
		more than 500g	8	6.1%	15	11.5%	8	4.5%	18	10.1%	0	0.0%	
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	
		refuse to answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	
					27	20.6%	27	20.6%	19	10.7%	19	10.7%	24
L12	What is the maximum quantity of beer ever drunk on one occasion	never drank beer	32	24.4%	24	18.3%	37	20.8%	38	21.3%	33	18.5%	
		1 bottle or less	40	30.5%	36	27.5%	78	43.8%	66	37.1%	72	40.4%	
		2-4 bottles	10	7.6%	11	8.4%	9	5.1%	8	4.5%	8	4.5%	
		5-6 bottles	1	0.8%	4	3.1%	3	1.7%	3	1.7%	3	1.7%	
		more than 6 bottles	9	6.9%	17	13.0%	8	4.5%	17	9.6%	1	0.6%	
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	
		refuse to answer	12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	
		no answer											



Q	Question text	Response category	CASES						CONTROLS					
			PROXY1		PROXY2		PROXY1		PROXY2		CONTROL			
			N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0
L13	What is the maximum quantity of wine ever drunk on one occasion	never drank wine up to 200g between 200 - 400g between 400 - 600g between 600 - 1000g more than 1 litre difficult to answer refuse to answer no answer	64	48.9%	65	49.6%	88	49.4%	90	50.6%	88	49.4%	88	49.4%
			6	4.6%	5	3.8%	15	8.4%	14	7.9%	9	5.1%	9	5.1%
			17	13.0%	11	8.4%	22	12.4%	21	11.8%	14	7.9%	14	7.9%
			7	5.3%	11	8.4%	11	6.2%	6	3.4%	13	7.3%	13	7.3%
			15	11.5%	7	5.3%	8	4.5%	8	4.5%	12	6.7%	12	6.7%
			4	3.1%	6	4.6%	6	3.4%	4	2.2%	5	2.8%	5	2.8%
			6	4.6%	14	10.7%	4	2.2%	8	4.5%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	37	20.8%
L14	What are the maximum quantity of spirits ever drunk on one occasion	never drank spirits between 50 - 100g between 100 - 200g between 200 - 300g between 300 - 400g between 400 - 500g more than 500g difficult to answer refuse to answer no answer	8	6.1%	7	5.3%	13	7.3%	14	7.9%	13	7.3%	13	7.3%
			7	5.3%	4	3.1%	9	5.1%	10	5.6%	4	2.2%	4	2.2%
			18	13.7%	15	11.5%	18	10.1%	16	9.0%	11	6.2%	11	6.2%
			21	16.0%	16	12.2%	31	17.4%	26	14.6%	22	12.4%	22	12.4%
			8	6.1%	6	4.6%	14	7.9%	17	9.6%	25	14.0%	25	14.0%
			29	22.1%	27	20.6%	37	20.8%	27	15.2%	42	23.6%	42	23.6%
			21	16.0%	28	21.4%	27	15.2%	19	10.7%	22	12.4%	22	12.4%
			7	5.3%	16	12.2%	5	2.8%	22	12.4%	2	1.1%	2	1.1%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	37	20.8%
L15	Does he ever drink spirits together with either beer or wine at the same sitting	yes, often yes, sometimes no, never difficult to answer refuse to answer no answer	19	14.5%	10	7.6%	7	3.9%	6	3.4%	1	0.6%	1	0.6%
			36	27.5%	33	25.2%	58	32.6%	44	24.7%	55	30.9%	55	30.9%
			60	45.8%	65	49.6%	84	47.2%	94	52.8%	85	47.8%	85	47.8%
			4	3.1%	11	8.4%	5	2.8%	7	3.9%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	37	20.8%
L16	Does he ever drink large quantities of spirits without also eating some food	often sometimes rarely/never difficult to answer refuse to answer no answer	13	9.9%	10	7.6%	7	3.9%	6	3.4%	2	1.1%	2	1.1%
			34	26.0%	35	26.7%	29	16.3%	19	10.7%	17	9.6%	17	9.6%
			66	50.4%	64	48.9%	114	64.0%	115	64.6%	122	68.5%	122	68.5%
			6	4.6%	10	7.6%	4	2.2%	11	6.2%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%	37	20.8%

**CONTROLS**

**CASES**

Q	Question text	Response category	PROXY1		PROXY2		PROXY1		PROXY2		CONTROL			
			N	%	N	%	N	%	N	%	N	%		
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0		
L17	How often does he become excessively drunk	every day	17	13.0%	9	6.9%	3	1.7%	1	0.6%	0	0.0%		
		several times a week	13	9.9%	22	16.8%	6	3.4%	9	5.1%	2	1.1%		
		once a week	8	6.1%	5	3.8%	4	2.2%	7	3.9%	3	1.7%		
		several times a month	10	7.6%	14	10.7%	7	3.9%	9	5.1%	4	2.2%		
		once a month	13	9.9%	17	13.0%	18	10.1%	15	8.4%	13	7.3%		
		less than once a month	22	16.8%	14	10.7%	36	20.2%	34	19.1%	27	15.2%		
		never or almost never	36	27.5%	37	28.2%	77	43.3%	72	40.4%	92	51.7%		
		difficult to answer	0	0.0%	1	0.8%	3	1.7%	3	1.7%	0	0.0%		
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%		
		no answer	12	9.2%	12	9.2%	24	13.5%	28	15.7%	37	20.8%		
					50	38.2%	49	37.4%	108	60.7%	113	63.5%	99	55.6%
		L18	Does he ever drink alcohol before noon	no	43	32.8%	48	36.6%	40	22.5%	28	15.7%	39	21.9%
yes, occasionally	23			17.6%	20	15.3%	6	3.4%	7	3.9%	3	1.7%		
yes, frequently	3			2.3%	2	1.5%	0	0.0%	2	1.1%	0	0.0%		
difficult to answer	0			0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%		
refuse to answer	12			9.2%	12	9.2%	24	13.5%	28	15.7%	37	20.8%		
no answer	18			13.7%	13	9.9%	3	1.7%	1	0.6%	0	0.0%		
L19	How often does he have a hangover	every day	12	9.2%	19	14.5%	6	3.4%	8	4.5%	2	1.1%		
		several times a week	6	4.6%	6	4.6%	2	1.1%	9	5.1%	4	2.2%		
		about once a week	10	7.6%	12	9.2%	9	5.1%	8	4.5%	7	3.9%		
		several times a month	15	11.5%	16	12.2%	17	9.6%	12	6.7%	16	9.0%		
		about once a month	12	9.2%	8	6.1%	28	15.7%	26	14.6%	28	15.7%		
		less than once a month	42	32.1%	39	29.8%	82	46.1%	73	41.0%	83	46.6%		
		never or almost never	3	2.3%	6	4.6%	7	3.9%	13	7.3%	1	0.6%		
		difficult to answer	1	0.8%	0	0.0%	0	0.0%	0	0.0%	0	0.0%		
		refuse to answer	12	9.2%	12	9.2%	24	13.5%	28	15.7%	37	20.8%		
		no answer												

Q	Question text	Response category	CASES						CONTROLS							
			PROXY1		PROXY2		PROXY1		PROXY2		PROXY1		PROXY2		CONTROL	
			N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0	178	100.0
L20	How often does he fail to fulfill his work obligations due to drinking alcohol	every day	0	0.0%	1	0.8%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		several times a week	3	2.3%	0	0.0%	0	0.0%	0	0.0%	1	0.6%	0	0.0%	0	0.0%
		about once a week	1	0.8%	1	0.8%	2	1.1%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		several times a month	2	1.5%	3	2.3%	1	0.6%	2	1.1%	0	0.0%	0	0.0%	0	0.0%
		about once a month	1	0.8%	3	2.3%	3	1.7%	2	1.1%	2	1.1%	1	0.6%	1	0.6%
		less than once a month	4	3.1%	4	3.1%	5	2.8%	4	2.2%	2	1.1%	2	1.1%	2	1.1%
		never	55	42.0%	54	41.2%	124	69.7%	120	67.4%	122	68.5%	122	68.5%	122	68.5%
		not applicable	52	39.7%	52	39.7%	19	10.7%	19	10.7%	16	9.0%	16	9.0%	16	9.0%
		difficult to answer	1	0.8%	1	0.8%	0	0.0%	2	1.1%	0	0.0%	0	0.0%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
	no answer	12	9.2%	12	9.2%	24	13.5%	28	15.7%	24	13.5%	28	15.7%	37	20.8%	
L21	How often does he fail to fulfill his family or personal obligations due to drinking alcohol	every day	11	8.4%	8	6.1%	4	2.2%	3	1.7%	1	0.6%	1	0.6%	1	0.6%
		several times a week	18	13.7%	18	13.7%	1	0.6%	3	1.7%	0	0.0%	0	0.0%	0	0.0%
		about once a week	1	0.8%	5	3.8%	5	2.8%	5	2.8%	0	0.0%	0	0.0%	0	0.0%
		several times a month	5	3.8%	6	4.6%	8	4.5%	10	5.6%	3	1.7%	3	1.7%	3	1.7%
		about once a month	7	5.3%	4	3.1%	10	5.6%	3	1.7%	6	3.4%	6	3.4%	6	3.4%
		less than once a month	4	3.1%	5	3.8%	10	5.6%	12	6.7%	18	10.1%	18	10.1%	18	10.1%
		never	68	51.9%	63	48.1%	116	65.2%	109	61.2%	113	63.5%	113	63.5%	113	63.5%
		difficult to answer	5	3.8%	10	7.6%	0	0.0%	5	2.8%	0	0.0%	0	0.0%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			no answer	12	9.2%	12	9.2%	24	13.5%	28	15.7%	24	13.5%	28	15.7%	37
L22	Does he ever go to sleep at night without taking his clothes off because of being drunk	every day	13	9.9%	7	5.3%	3	1.7%	1	0.6%	0	0.0%	0	0.0%	0	0.0%
		several times a week	12	9.2%	19	14.5%	5	2.8%	8	4.5%	0	0.0%	0	0.0%	0	0.0%
		about once a week	10	7.6%	4	3.1%	2	1.1%	3	1.7%	0	0.0%	0	0.0%	0	0.0%
		several times a month	11	8.4%	14	10.7%	3	1.7%	4	2.2%	3	1.7%	3	1.7%	3	1.7%
		about once a month	2	1.5%	7	5.3%	4	2.2%	9	5.1%	5	2.8%	5	2.8%	5	2.8%
		less than once a month	6	4.6%	11	8.4%	16	9.0%	10	5.6%	10	5.6%	10	5.6%	10	5.6%
		never or almost never	65	49.6%	56	42.7%	121	68.0%	112	62.9%	122	68.5%	122	68.5%	122	68.5%
		difficult to answer	0	0.0%	1	0.8%	0	0.0%	3	1.7%	1	0.6%	1	0.6%	1	0.6%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			no answer	12	9.2%	12	9.2%	24	13.5%	28	15.7%	24	13.5%	28	15.7%	37

Q	Question text	Response category	CASES				CONTROLS					
			PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2	CONTROL	CONTROL		
			N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0
L23	Does he ever drink alone	yes, often yes, sometimes no, never difficult to answer refuse to answer no answer	32	24.4%	35	26.7%	16	9.0%	14	7.9%	6	3.4%
		usually at home	48	36.6%	51	38.9%	58	32.6%	58	32.6%	45	25.3%
L24	Does he usually drink alcohol at home or in other places	sometimes at home, sometimes elsewhere usually elsewhere difficult to answer refuse to answer no answer	57	43.5%	59	45.0%	76	42.7%	78	43.8%	74	41.6%
			13	9.9%	8	6.1%	18	10.1%	14	7.9%	22	12.4%
			1	0.8%	1	0.8%	2	1.1%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	28	15.7%	37	20.8%
L25	Has he had one or more episodes of zaponi in the past year	yes, often yes, sometimes no, never difficult to answer refuse to answer no answer	28	21.4%	26	19.8%	8	4.5%	6	3.4%	4	2.2%
			18	13.7%	21	16.0%	9	5.1%	9	5.1%	7	3.9%
			73	55.7%	72	55.0%	137	77.0%	135	75.8%	129	72.5%
			0	0.0%	0	0.0%	0	0.0%	1	0.6%	1	0.6%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			12	9.2%	12	9.2%	24	13.5%	27	15.2%	37	20.8%
L26	Has he had one or more episodes of zaponi in the past month	yes no difficult to answer refuse to answer no answer	29	22.1%	31	23.7%	12	6.7%	11	6.2%	5	2.8%
			17	13.0%	15	11.5%	4	2.2%	3	1.7%	6	3.4%
			0	0.0%	1	0.8%	1	0.6%	1	0.6%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			85	64.9%	84	64.1%	161	90.4%	163	91.6%	167	93.8%
			24	18.3%	24	18.3%	7	3.9%	7	3.9%	3	1.7%
			5	3.8%	7	5.3%	5	2.8%	4	2.2%	2	1.1%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
L27	Has he had one or more episodes of zaponi in the past week	difficult to answer refuse to answer no answer	102	77.9%	100	76.3%	166	93.3%	167	93.8%	173	97.2%

Q	Question text	Response category	CASES			CONTROLS						
			PROXY1	PROXY2	PROXY1	PROXY2	CONTROL					
			N	%	N	%	N	%				
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0		
L28	During his most recent period of heavy drinking, what was the maximum quantity of beer drunk	none 1 bottle or less 2-4 bottles 5-6 bottles more than 6 bottles drank beer, but not sure of the quantity difficult to answer refuse to answer no answer	13 1 3 0 0	9.9% 0.8% 2.3% 0.0% 0.0%	16 0 2 1 1	12.2% 0.0% 1.5% 0.8% 0.8%	6 0 0 0 0	3.4% 0.0% 0.0% 0.0% 0.0%	3 1 0 0 0	1.7% 0.6% 0.0% 0.0% 0.0%	2 0 1 0 0	1.1% 0.0% 0.6% 0.0% 0.0%
L29	During his most recent period of heavy drinking, what was the maximum quantity of wine drunk	never drank wine up to 200g between 200 - 400g between 400 - 600g between 600 - 1000g more than 1 litre drank wine, but not sure of the quantity difficult to answer refuse to answer no answer	18 0 1 0 2 0	13.7% 0.0% 0.8% 0.0% 1.5% 0.0%	19 0 1 1 1 1	14.5% 0.0% 0.8% 0.8% 0.8% 0.8%	5 0 0 0 0 0	2.8% 0.0% 0.0% 0.0% 0.0% 0.0%	4 0 0 0 1 0	2.2% 0.0% 0.0% 0.0% 0.6% 0.0%	2 0 0 0 1 0	1.1% 0.0% 0.0% 0.0% 0.6% 0.0%
L30	During his most recent period of heavy drinking, what was the maximum quantity of spirits drunk	none between 50 - 100g between 100 - 200g between 200 - 300g between 300 - 400g between 400 - 500g more than 500g drank spirits, but not sure of the quantity difficult to answer refuse to answer no answer	13 0 0 0 1 1 2	9.9% 0.0% 0.0% 0.0% 0.8% 0.8% 1.5%	8 0 1 0 1 2 3	6.1% 0.0% 0.8% 0.0% 0.8% 1.5% 2.3%	2 0 0 0 0 0 2	1.1% 0.0% 0.0% 0.0% 0.0% 0.0% 1.1%	0 0 0 1 0 0 2	0.0% 0.0% 0.0% 0.6% 0.0% 0.0% 1.1%	0 0 0 0 1 1	0.0% 0.0% 0.0% 0.6% 0.6% 0.6% 0.6%
			107	81.7%	107	81.7%	171	96.1%	171	96.1%	175	98.3%

Q	Question text	Response category	CASES						CONTROLS							
			PROXY1		PROXY2		PROXY1		PROXY2		PROXY1		PROXY2		CONTROL	
			N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0	178	100.0
L31	During his most recent period of heavy drinking, did he drink any other alcoholic substances	yes no difficult to answer refuse to answer no answer	22 2 0 0 107	16.8% 1.5% 0.0% 0.0% 81.7%	21 2 1 0 107	16.0% 1.5% 0.8% 0.0% 81.7%	5 2 0 0 171	2.8% 1.1% 0.0% 0.0% 96.1%	3 2 2 0 171	1.7% 1.1% 1.1% 0.0% 96.1%	1 2 0 0 175	0.6% 1.1% 0.0% 0.0% 98.3%	1 2 0 0 175	0.6% 1.1% 0.0% 0.0% 98.3%		
L32	Has he been arrested because of being drunk during the past year	yes no difficult to answer refuse to answer no answer	18 100 1 0 12	13.7% 76.3% 0.8% 0.0% 9.2%	16 101 2 0 12	12.2% 77.1% 1.5% 0.0% 9.2%	10 144 0 0 24	5.6% 80.9% 0.0% 0.0% 13.5%	11 135 5 0 27	6.2% 75.8% 2.8% 0.0% 15.2%	6 135 0 0 37	3.4% 75.8% 0.0% 0.0% 20.8%	6 135 0 0 37	3.4% 75.8% 0.0% 0.0% 20.8%		
L33	Does he currently drink more, less or about the same as one year ago	more than a year before about the same as a year before less than a year before difficult to answer refuse to answer no answer	35 46 38 0 0 12	26.7% 35.1% 29.0% 0.0% 0.0% 9.2%	16 62 40 1 0 12	12.2% 47.3% 30.5% 0.8% 0.0% 9.2%	26 84 40 4 0 24	14.6% 47.2% 22.5% 2.2% 0.0% 13.5%	12 95 40 4 0 27	6.7% 53.4% 22.5% 2.2% 0.0% 15.2%	6 76 57 2 0 37	3.4% 42.7% 32.0% 1.1% 0.0% 20.8%	6 76 57 2 0 37	3.4% 42.7% 32.0% 1.1% 0.0% 20.8%		
L34	Does he currently drink more, less or the same as one month ago	about the same as a month before less than a month before difficult to answer refuse to answer no answer	47 47 3 0 12	35.9% 35.9% 2.3% 0.0% 9.2%	59 48 4 0 12	45.0% 36.6% 3.1% 0.0% 9.2%	109 34 4 0 24	61.2% 19.1% 2.2% 0.0% 13.5%	108 33 5 0 27	60.7% 18.5% 2.8% 0.0% 15.2%	90 43 1 0 37	50.6% 24.2% 0.6% 0.0% 20.8%	90 43 1 0 37	50.6% 24.2% 0.6% 0.0% 20.8%		
L35	Has there been any period when he drank heavily other than during the past 12 months	yes no difficult to answer refuse to answer no answer	62 65 4 0 0	47.3% 49.6% 3.1% 0.0% 0.0%	60 57 14 0 0	45.8% 43.5% 10.7% 0.0% 0.0%	82 91 5 0 0	46.1% 51.1% 2.8% 0.0% 0.0%	69 96 13 0 0	38.8% 53.9% 7.3% 0.0% 0.0%	76 88 0 0 14	42.7% 49.4% 0.0% 0.0% 7.9%	76 88 0 0 14	42.7% 49.4% 0.0% 0.0% 7.9%		

Q	Question text	Response category	CASES				CONTROLS					
			PROXY1	PROXY2	PROXY1	PROXY2	PROXY1	PROXY2	CONTROL			
			N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0
L36	Has he ever had help or advice from a doctor, narcologist, social worker or some other professional for an alcohol problem	yes	28	21.4%	26	19.8%	29	16.3%	25	14.0%	26	14.6%
		no	103	78.6%	98	74.8%	149	83.7%	146	82.0%	138	77.5%
		difficult to answer	0	0.0%	7	5.3%	0	0.0%	7	3.9%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
L37	Did he get such help during the past year	no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
		yes	11	8.4%	9	6.9%	5	2.8%	4	2.2%	5	2.8%
		no	17	13.0%	18	13.7%	23	12.9%	20	11.2%	21	11.8%
		difficult to answer	0	0.0%	0	0.0%	1	0.6%	1	0.6%	0	0.0%
L38	Has he ever been taken to a sobering up centre	refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	103	78.6%	104	79.4%	149	83.7%	153	86.0%	152	85.4%
		yes	82	62.6%	75	57.3%	84	47.2%	65	36.5%	79	44.4%
		no	45	34.4%	42	32.1%	93	52.2%	97	54.5%	85	47.8%
L39	Was this during the past year	difficult to answer	4	3.1%	14	10.7%	1	0.6%	16	9.0%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
		yes	21	16.0%	18	13.7%	12	6.7%	16	9.0%	7	3.9%
M1	Is he a current smoker	no	61	46.6%	52	39.7%	71	39.9%	46	25.8%	72	40.4%
		difficult to answer	0	0.0%	5	3.8%	1	0.6%	3	1.7%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	49	37.4%	56	42.7%	94	52.8%	113	63.5%	99	55.6%
M2	How many years ago did he stop smoking regularly	never a smoker	15	11.5%	16	12.2%	35	19.7%	38	21.3%	31	17.4%
		no, ex-smoker	9	6.9%	10	7.6%	31	17.4%	27	15.2%	31	17.4%
		yes, a current smoker	107	81.7%	105	80.2%	112	62.9%	112	62.9%	102	57.3%
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	1	0.6%	0	0.0%
M2	How many years ago did he stop smoking regularly	refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
		less than one year before death	0	0.0%	4	3.1%	3	1.7%	3	1.7%	3	1.7%
		>1 year, < 5 years before death	4	3.1%	3	2.3%	4	2.2%	4	2.2%	4	2.2%
M2	How many years ago did he stop smoking regularly	>5 years, < 10 years before death	1	0.8%	0	0.0%	5	2.8%	7	3.9%	7	3.9%
		more than 10 years before death	4	3.1%	3	2.3%	19	10.7%	13	7.3%	16	9.0%
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	0.6%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	122	93.1%	121	92.4%	147	82.6%	151	84.8%	147	82.6%

Q	Question text	Response category	CASES						CONTROLS							
			PROXY1		PROXY2		PROXY1		PROXY2		PROXY1		PROXY2		CONTROL	
			N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0	178	100.0
M3	What does he smoke most often (other)	papyrosi filtered cigarettes unfiltered cigarettes other (specify) difficult to answer refuse to answer no answer	1	0.8%	1	0.8%	2	1.1%	2	1.1%	3	1.7%	3	1.7%	3	1.7%
			78	59.5%	76	58.0%	118	66.3%	106	59.6%	114	64.0%	114	64.0%	114	64.0%
			31	23.7%	33	25.2%	14	7.9%	11	6.2%	15	8.4%	15	8.4%	15	8.4%
			4	3.1%	4	3.1%	0	0.0%	1	0.6%	1	0.6%	1	0.6%	1	0.6%
			2	1.5%	1	0.8%	9	5.1%	19	10.7%	0	0.0%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			15	11.5%	16	12.2%	35	19.7%	39	21.9%	45	25.3%	45	25.3%	45	25.3%
			15	11.5%	13	9.9%	7	3.9%	10	5.6%	7	3.9%	7	3.9%	7	3.9%
			18	13.7%	15	11.5%	24	13.5%	16	9.0%	22	12.4%	22	12.4%	22	12.4%
M4	When he smoked, how many per day was usual	1-5 per day 6-10 per day 11-20 per day more than 20 per day difficult to answer refuse to answer no answer	60	45.8%	54	41.2%	68	38.2%	62	34.8%	84	47.2%	84	47.2%	84	47.2%
			14	10.7%	14	10.7%	16	9.0%	9	5.1%	20	11.2%	20	11.2%	20	11.2%
			9	6.9%	19	14.5%	28	15.7%	42	23.6%	0	0.0%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			15	11.5%	16	12.2%	35	19.7%	39	21.9%	45	25.3%	45	25.3%	45	25.3%
			3	2.3%	3	2.3%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			56	42.7%	39	29.8%	63	35.4%	42	23.6%	84	47.2%	84	47.2%	84	47.2%
M5	How old was he when he started smoking regularly	<10 years old 10-19 years old 20-29 years old >30 years old difficult to answer refuse to answer no answer	32	24.4%	30	22.9%	37	20.8%	35	19.7%	44	24.7%	44	24.7%	44	24.7%
			6	4.6%	6	4.6%	3	1.7%	4	2.2%	5	2.8%	5	2.8%	5	2.8%
			19	14.5%	37	28.2%	40	22.5%	58	32.6%	0	0.0%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			15	11.5%	16	12.2%	35	19.7%	39	21.9%	45	25.3%	45	25.3%	45	25.3%
			77	58.8%	58	44.3%	109	61.2%	92	51.7%	116	65.2%	116	65.2%	116	65.2%
			1	0.8%	0	0.0%	1	0.6%	0	0.0%	1	0.6%	1	0.6%	1	0.6%
			1	0.8%	1	0.8%	2	1.1%	3	1.7%	4	2.2%	4	2.2%	4	2.2%
M6	Have his parents ever smoked	yes, father only yes, mother only yes, both parents no, neither difficult to answer refuse to answer no answer	23	17.6%	23	17.6%	37	20.8%	28	15.7%	36	20.2%	36	20.2%	36	20.2%
			29	22.1%	49	37.4%	29	16.3%	55	30.9%	7	3.9%	7	3.9%	7	3.9%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
			0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%



Q	Question text	Response category	CASES						CONTROLS					
			PROXY1		PROXY2		PROXY1		PROXY2		CONTROL			
			N	%	N	%	N	%	N	%	N	%	N	%
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0
E15	What is his marital status?	living with registered spouse	102	77.9%	100	76.3%	160	89.9%	158	88.8%	149	83.7%	15	8.4%
		living with unregistered spouse	23	17.6%	23	17.6%	16	9.0%	18	10.1%	15	8.4%	0	0.0%
		divorced/separated	6	4.6%	8	6.1%	2	1.1%	1	0.6%	0	0.0%	0	0.0%
		widower	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		never married	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	1	0.6%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
F1	What is his level of education?	no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
		some/complete secondary	64	48.9%	45	34.4%	61	34.3%	45	25.3%	63	35.4%	31	17.4%
		professional school	34	26.0%	32	24.4%	39	21.9%	32	18.0%	31	17.4%	40	22.5%
		specialised secondary	22	16.8%	32	24.4%	45	25.3%	46	25.8%	40	22.5%	30	16.9%
		some/complete higher	11	8.4%	12	9.2%	33	18.5%	33	18.5%	30	16.9%	0	0.0%
		difficult to answer	0	0.0%	10	7.6%	0	0.0%	22	12.4%	0	0.0%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
F3	Is he in regular paid employment?	no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%
		yes	61	46.6%	59	45.0%	154	86.5%	151	84.8%	139	78.1%	17	9.6%
		no, for reasons unrelated to ill health	31	23.7%	32	24.4%	17	9.6%	17	9.6%	17	9.6%	7	3.9%
		no, due to invalidity	35	26.7%	34	26.0%	6	3.4%	8	4.5%	7	3.9%	1	0.6%
		no, for reasons related to ill health	4	3.1%	5	3.8%	1	0.6%	2	1.1%	1	0.6%	0	0.0%
		difficult to answer	0	0.0%	1	0.8%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%

**CASES**

**CONTROLS**

Q	Question text	Response category	PROXY1			PROXY2			PROXY1			PROXY2			CONTROL		
			N	%	N	%	N	%	N	%	N	%	N	%	N	%	
	<b>TOTAL</b>		131	100.0	131	100.0	178	100.0	178	100.0	178	100.0	178	100.0	178	100.0	
C14	Does his household own a car?	yes	96	26.7%	94	28.2%	89	50.0%	91	51.1%	80	44.9%					
		no	35	73.3%	37	71.8%	89	50.0%	87	48.9%	84	47.2%					
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
J8	Is he registered disabled?	no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%					
		yes	91	30.5%	91	29.8%	165	92.7%	164	92.1%	150	84.3%					
		no	40	69.5%	39	69.5%	13	7.3%	14	7.9%	14	7.9%					
		difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
K1	Has he had any broken bones in the past year?	refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		no answer	0	0.0%	1	0.8%	0	0.0%	0	0.0%	14	7.9%					
		yes	14	10.7%	11	8.4%	9	5.1%	9	5.1%	5	2.8%					
		no	117	89.3%	120	91.6%	169	94.9%	169	94.9%	159	89.3%					
K2	Does he usually cough in the morning?	difficult to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%					
		often	60	45.8%	55	42.0%	57	32.0%	33	18.5%	32	18.0%					
K3	In the past few months, could he climb up a flight up of stairs without becoming breathless?	sometimes	22	16.8%	20	15.3%	37	20.8%	37	20.8%	34	19.1%					
		rarely	4	3.1%	8	6.1%	11	6.2%	20	11.2%	15	8.4%					
		never	45	34.4%	45	34.4%	71	39.9%	77	43.3%	83	46.6%					
		difficult to answer	0	0.0%	3	2.3%	2	1.1%	11	6.2%	0	0.0%					
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%					
		yes, easily	69	52.7%	68	51.9%	152	85.4%	155	87.1%	150	84.3%					
		yes, with some difficulty	37	28.2%	37	28.2%	19	10.7%	12	6.7%	12	6.7%					
		no, too difficult	24	18.3%	18	13.7%	2	1.1%	3	1.7%	2	1.1%					
		difficult to answer	1	0.8%	8	6.1%	5	2.8%	8	4.5%	0	0.0%					
		refuse to answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%					
		no answer	0	0.0%	0	0.0%	0	0.0%	0	0.0%	14	7.9%					

## **Appendix 8**

### **Frequency of responses to questions about frequency of alcohol consumption by respondent type**

**Table 1.1 All households**

		Case proxy	Control proxy	Control
<b>beer</b>	<b>daily</b>	13.4% (170)	7.0% (79)	5.2% (59)
	<b>weekly</b>	31.4% (400)	36.2% (409)	37.0% (422)
	<b>monthly</b>	25.7% (327)	31.8% (359)	30.6% (349)
	<b>rarely/never</b>	29.5% (376)	25.0% (283)	27.2% (310)
<b>wine</b>	<b>daily</b>	6.7% (85)	1.0% (11)	0.3% (3)
	<b>weekly</b>	10.7% (135)	5.8% (65)	5.2% (59)
	<b>monthly</b>	21.9% (278)	31.5% (355)	28.9% (329)
	<b>rarely/never</b>	60.7% (769)	61.8% (697)	65.7% (749)
<b>spirits</b>	<b>daily</b>	12.8% (162)	2.9% (33)	2.0% (23)
	<b>weekly</b>	30.3% (384)	23.4% (265)	24.8% (283)
	<b>monthly</b>	39.1% (496)	52.4% (593)	52.4% (597)
	<b>rarely/never</b>	17.8% (226)	21.2% (240)	20.7% (236)
<b>surrogates</b>	<b>daily</b>	23.8% (303)	1.9% (21)	0.9% (10)
	<b>weekly</b>	11.8% (150)	2.8% (31)	2.1% (24)
	<b>monthly</b>	5.7% (73)	3.6% (40)	3.4% (39)
	<b>rarely/never</b>	58.6% (746)	91.8% (1,033)	93.6% (1,067)

*Table 1.2 Households with spouses as proxy*

		Case proxy	Control proxy	Control
beer	daily	11.9% (92)	7.0% (69)	4.9% (48)
	weekly	31.6% (245)	36.6% (358)	37.8% (372)
	monthly	25.9% (201)	30.9% (303)	29.6% (291)
	rarely/never	30.6% (237)	25.4% (249)	27.7% (273)
wine	daily	5.0% (39)	0.9% (9)	0.2% (2)
	weekly	11.1% (86)	5.5% (54)	5.2% (51)
	monthly	21.7% (168)	32.3% (316)	28.8% (283)
	rarely/never	62.1% (480)	61.2% (598)	65.9% (648)
spirits	daily	11.5% (89)	3.1% (30)	2.0% (20)
	weekly	31.9% (246)	24.2% (237)	25.6% (252)
	monthly	40.2% (310)	52.0% (509)	51.6% (507)
	rarely/never	16.5% (127)	20.7% (203)	20.8% (204)
surrogates	daily	18.8% (145)	1.4% (14)	0.8% (8)
	weekly	10.0% (77)	2.7% (26)	1.9% (19)
	monthly	6.0% (46)	3.5% (34)	2.9% (29)
	rarely/never	65.2% (502)	92.4% (899)	94.3% (928)

**Table 1.3** *Households with proxy who reported 'good' or 'excellent' knowledge of the index*

		Case proxy	Control proxy	Control
<b>beer</b>	daily	11.0% (112)	6.1% (59)	5.0% (48)
	weekly	31.0% (315)	36.4% (351)	37.4% (362)
	monthly	27.4% (278)	32.7% (315)	30.5% (295)
	rarely/never	30.5% (310)	24.8% (239)	27.1% (262)
<b>wine</b>	daily	6.4% (65)	0.8% (8)	0.2% (2)
	weekly	10.0% (102)	5.5% (53)	5.1% (49)
	monthly	22.3% (227)	31.1% (299)	28.6% (277)
	rarely/never	61.3% (624)	62.5% (601)	66.1% (639)
<b>spirits</b>	daily	11.5% (117)	2.8% (27)	2.0% (19)
	weekly	28.5% (290)	22.3% (215)	24.6% (238)
	monthly	40.4% (411)	52.8% (508)	52.0% (502)
	rarely/never	19.6% (200)	22.0% (212)	21.4% (207)
<b>surrogates</b>	daily	22.0% (223)	1.7% (16)	0.8% (8)
	weekly	11.7% (119)	2.6% (25)	2.0% (19)
	monthly	5.9% (60)	2.9% (28)	2.8% (27)
	rarely/never	60.4% (612)	92.8% (888)	94.4% (913)